

**ACCOUNTABILITY, VEDIC & SCHUMACHER'S PHILOSOPHY AND  
AUTOETHNOGRAPHY:  
AN ADVOCATION FOR TAX RELIEF FOR SIBLING CAREGIVERS IN  
MALAYSIA**

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**THESIS SUBMITTED IN FULFILMENT  
OF THE REQUIREMENTS  
FOR THE DEGREE OF DOCTOR OF PHILOSOPHY**

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KUALA LUMPUR, MALAYSIA**

**SEPTEMBER 2015**

## ABSTRACT

In line with its objective of being accountable to Malaysian society, the Government of Malaysia has shown full support for all efforts to enhance facilities for persons with disabilities and ensuring that these individuals are always well taken care of. This is evident from the enactment of the *Persons with Disabilities Act 2008*, and the signing of the instrument to ratify the United Nations *Convention on the Rights of Persons with Disabilities*. The government has recognised that caring for persons with disabilities is its responsibility but, judging from the sheer enormity of the number of such persons, this responsibility has been delegated to the individual families of the disabled over time, with the government providing assistance in numerous forms.

The study raises the questions of why and how the (formal and moral) accountability operates within the context of religion, society and state and serves the underprivileged or marginalised people's interest such as disabled in the Malaysian society.

The study endeavours to understand what motivates siblings to become caregivers and to this end attempts to develop a theoretical conceptualisation of accountability firstly by drawing from Vedic philosophy and secondly by providing an explanation from the philosophy of Schumacher.

With this in place, the study advances to explore the state's role in supporting sibling caregivers.

One form in which the State is able to support the families of persons with disabilities is through the provision of tax relief, which serves to reduce their income tax payable. This is meant to compensate them for the additional costs incurred in providing caregiving services. Although the relief never covers the full amount of costs incurred, it does provide some financial recompense. Additionally, the relief represents recognition of their contribution in taking care of a disabled person, thus providing caregivers a balm of satisfaction.

Unfortunately, following the lineal ancestry principle, the tax relief is given only to parents taking care of children with disabilities, or to children taking care of their aged, sick or disabled parents but there is no tax relief available in Malaysia to sibling caregivers. Interestingly, many other countries, including our immediate geographical neighbours of Thailand and Singapore, provide tax relief and credits to caregivers, irrespective of the relationship between them and the person to whom care is provided.

As there is limited research in the area of what motivates siblings to become caregivers, especially in Malaysia, this study draws on the concept of accountability in existing literature (as viewed through the lens of Schumacher, a renowned philosopher), as well as from the principles expounded by the Vedas, to understand this motivation of sibling caregivers. In line with this motivation, this study intends to explore the state's role in supporting sibling caregivers. One suggestion is for the Government to provide a tax relief for sibling caregivers with both a token of compensation for the costs they have borne, as well as recognition of their personal, selfless contribution.

This study is significant as it contributes to the literature in three aspects. First, it develops a conceptualisation of accountability viewed through the theoretical lens using Schumacher,

and draws on Vedic philosophy to empirically examine the issue of motivation for sibling caregivers. Second, it uses the autoethnographic approach to suggest that the role of the State could be discharged through the introduction of a tax relief for sibling caregivers. Finally, it provides empirical evidence and support to guide policy direction with a view to harmonisation of fiscal policies within the geographical region.

## **ACKNOWLEDGEMENTS**

In this demanding and arduous journey of completing my thesis, there are many people who have contributed their time, knowledge and support. Although I am unable to mention each and every person, there are a special few without whom this thesis would not have been finished.

My greatest gratitude is to the Almighty Lord who has been a constant companion throughout this journey, inspiring my spirit and uplifting it in my moments of desperation and despair.

Secondly I want to thank all the sibling caregivers who have willingly told their family stories and explained the trials and tribulations that they had endured thus enabling me to compile a detailed analysis to convince the Government of Malaysia that the introduction of a tax relief for sibling caregivers is imperative.

Lastly, I acknowledge the debt I owe to my first supervisor, Professor Dr. Susela Devi. She has always been a pillar of support, a reservoir of encouragement and a beacon of guidance throughout this adventurous academic research journey. I am greatly indebted to her for the substantial hours spent to help improve the quality of this thesis. She has also been a great mentor, advisor and an endless source of inspiration. Also, my second supervisor Associate Professor Dr. Choong Kwai Fatt, whose valuable comments and opinions for improvements have assisted me to mould this final product.

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## **CHAPTER 1**

### **OVERVIEW OF RESEARCH**

#### **1.1. INTRODUCTION**

Since the dawn of time, the duty of the King has been to take care of the aged, persons with disabilities and orphaned children. Now, with the advent of constitutional democracies and monarchies, the government (amongst others) has assumed this role. Miles (2002b, p.124) expresses that one of the duties of the state is the “charitable provision”, which also encompasses the features of kindness and concern. As the sovereign rarely had a source of income, a system of taxation was introduced so that when the citizens of a country earned income, a contribution was made to the Crown to facilitate the dispensing of its charitable duties. This concept was born from religious practices such as the payment of tithes by the Christians, and that of *Zakat* by the Muslims. Taxes, and their related cousins consisting of levies, duties and tolls, represent the main avenue for government to ensure the sufficiency of funds to finance all its proposed undertakings (Mayson & Blake, 1990, p.1).

However, as the population grew, society progressed and the concept of family became steadfast. The baton of caregiving was gradually passed on to the family, with government providing general welfare services. This delegation of this caregiving duty by the Government to the families with the former providing support gave birth to a new conceptualisation of accountability. The Government is accountable to the caregivers who

have acceptable this task from the Government and accordingly the Government is responsible to ensure that the caregivers are able to carry out these duties with ease. To this end the Government should make available to the caregiver all facilities necessary to discharge these duties effectively.

A distinct variance can be identified, however, between the lives of families undertaking the caregiver responsibility as opposed to those that are not. Recognising this inequity, efforts were made by relevant government authorities to promote justice and fairness by creating a level playing field for all families. Many facilities were constructed for the disabled, concessions were made in their favour, discounts were given for use of amenities and relief was endowed to lessen the financial burden on their families. In many cases, however, the disabled could not enjoy these amenities, either because the facilities were inaccessible, or they were unsuitable for people with certain types of disabilities. In moments like this we need to put on our thinking caps to produce new ideas that would literally benefit the persons with disabilities.

In addition the caregiver is also accountable to the persons under their care and has an unwritten obligation to fulfill their responsibilities efficiently and effectually. This study explains this new form of accountability by drawing from principles enshrined in the Vedas (Hindu scriptures). It serves to explain why a caregiver would voluntarily accept such a difficult task by using the principles of Karma and the general religious outlook on persons with disabilities and caregiving.

The study further lends support to the concepts of accountability to persons with disabilities and understanding the adoption of the task of caregiving by reaching into the philosophies expounded by Schumacher,

The study then proceeds to deliberate on the role of the state in ensuring that such accountability can be effectively discharged.

In Malaysia, there were many concessions, allowances, reliefs and benefits given to persons with disabilities which they were not able to use. The authorities eventually extended these benefits to caregivers, but confined their use to the parents, spouse or children of persons with disabilities. Many persons with disabilities do not marry and remain under the care of their parents. However, upon the death of the parents, or when the parents are too old or sick to take care of them, siblings (in many cases) will step in to take care of them. In many parts of the *Income Tax Act 1967*, references to “immediate family” refer to parents, spouses or children, and never siblings.<sup>1</sup>Corresponding with this culture, the lone tax relief for caregivers in the *Income Tax Act 1967* is extended only to children taking care of their parents.

The implications of this study is that The Government should provide support to sibling caregivers and suggests that an avenue to successfully administer this support would be through the introduction of a tax relief for the sibling caregivers.

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<sup>1</sup>Refer to Sections 7(1)(b) and 13(1)(b) and Public Rulings 2/2004 and 6/2011.



This study adopts an interpretative perspective and stance, and aims to raise substantive dialectics to explain what motivates siblings to become caregivers using Vedic principles and Schumacher's philosophy and what the role of the State is in this whole endeavour. The approach is qualitative, while the methodology is an autoethnographic endeavour; the experience of being a sibling caregiver for a person with disabilities has enabled the researcher to position himself in the research process, immerse himself in the research objectives, establish rapport with the other participants and be a component of the final thesis (Ellis 2004, p.30). The researcher embraces a dual role, one of being the researcher and another, of being a member of the "sub-culture or family" of sibling caregivers. My inclusion in the study as the research instrument, as both researcher and subject simultaneously, has served to enhance the effectiveness and understanding of the position.

The remaining discussion in this chapter is structured as follows. Section 1.2 discusses the background of the study, including gaps in the extant literature on tax relief for sibling caregivers, the tax climate in other countries in relation to such relief and existing literature advocating a system of recompense for sibling caregivers. Section 1.3 describes the problem statement whilst Section 1.4 presents the research questions. Section 1.5 provides the research objectives; Section 1.6 discusses the methodology and research design whereas Section 1.7 elaborates on the research motivation and contribution. Section 1.8 highlights the significance of the study and lastly Section 1.9 describes the structure of the thesis.

## **1.2. BACKGROUND OF THE STUDY**

Selwyn & Nandy (2011) bemoan that although extensive research exists on caregivers (referred to as “carers” in their study), particularly grandparents, there is very little on sibling carers. They comment that their study is the pioneer attempt to describe “sibling carers in England.” They encourage further research on sibling caregivers in terms of their prevalence in other countries, whether the motivation for undertaking the task resembles that of grandparent carers and what circumstances are peculiar to sibling caregivers as opposed to other caregivers.

The world is slowly recognising the trend of sibling caregiving and is providing these caregivers with special tax relief. Indeed, tax relief is awarded to sibling caregivers under the tax regimes of both Singapore and Thailand, two of Malaysia’s immediate neighbours. The Singapore tax authority awards a deduction for the maintenance of handicapped siblings incapacitated by reason of physical or mental infirmity by any dependant living in Singapore, including one who is his spouse’s brother or sister. The Singapore tax authority’s counterpart in Thailand allows taxpayers that actually support qualifying disabled persons to take an allowance.

Further, Canada’s 2011 Budget (retrieved from [www.patriciadavidson.ca/.../the-next-phase-of-canada-s-economic-ac](http://www.patriciadavidson.ca/.../the-next-phase-of-canada-s-economic-ac)) emphasised that the Canadian Government appreciates and acknowledges the sacrifices made by caregivers to their family members in spite of being bread winners and this is evident in its continuous efforts to “lighten their load”. India offers a deduction of Rs. 50,000 for supporting a disabled dependent, and a deduction of Rs. 75,000 if the dependent has a severe disability. In Ireland, taxpayers can claim the Dependent

Relative Tax Credit if they maintain at their own expense, a relative (including a relative of their spouse) who is unable, due to old age or infirmity, to maintain him or herself. The United States recognises that sacrifices made by caregivers of persons with disabilities both financial and non-financial and accordingly the US Internal Revenue Service (IRS) allows such caregivers to claim a dependant relief in respect of the persons that they care, for in computing their income tax payable. France gives an allowance against the cost of specific works to give greater mobility or safety to elderly or disabled persons in the home. New Zealand provides a housekeeper rebate, while Australia has an invalid relative rebate.

Studies such as those undertaken by Silverstein & Parrott (2001) and the British Columbia Law Institute (2009) have reported on the prevalence of sibling caregivers. Other studies (Welch et al., 2012; Williams et al., 2010, etc.) illustrate the problems faced by these siblings as they undertake the caregiving responsibility. The task of caregiving involves a whole new impact on the life of the caregiver: it entails sacrifices and the curtailment of personal enjoyment and personal time, it encroaches on their work and it affects them psychologically.

As explained earlier, since the role of caregiving was originally that of the government, a transfer of the role should be accompanied by commensurate compensation. Studies by Seltzer et al., 1997; Yanagisawaa et al., 2010; and Selwyn & Nandy, 2011 have all emphasised the need for a scheme to recompense the sibling caregiver. The British Columbia Law Institute (2009) in its report proclaims that although tax relief might not provide a monumental financial relief, it is nevertheless an apparatus capable of illustrating the financial burdens borne by the caregiver and also acts as a channel to convey economic benefits to them.

Children with disabilities deserve a chance to grow up as “psychologically healthy adults with firmly established positive interpersonal relationships” and this can be achieved if society provides the necessary support to children with disabilities and their siblings (Stoneman, 2005, p.347 as quoted by Tsao, 2012). However she laments the lack of empirical studies endeavouring to lend support to policies attempting to “develop positive and mutually satisfying relationships” between siblings which otherwise would have served to enhance a “positive rather than negative outcomes of sibling relationship development” (citing Mascha & Boucher, 2006). Therefore, Tsao et al. (2012, p.53) conclude “that empowering siblings to be effective intervention partners” will produce advantages not only for the siblings (both the abled and disabled) but also for the family as a whole. One source of such empowerment would be through the granting of tax relief.

However, the arguments raised in these studies do not draw upon any substantive theoretical justification to make a case. Therefore, this study attempts to provide an understanding of what motivates sibling caregivers by developing the concept of accountability in the context of religion, whilst adopting an autoethnographic approach to provide an analysis of empirical data.

### **1.3. PROBLEM STATEMENT**

The Malaysian government has shown that it cares for persons with disabilities. This is evident in the enactment of the *Persons with Disabilities Act 2008*(which was gazetted on 24 January 2008), the signing of the instrument to ratify the United Nations *Convention on the Rights of Persons with Disabilities* on 6 July 2010 and the range of tax reliefs provided to/for persons with disabilities.

However, government recognition for caregivers is only now seeing the light of day through the introduction of a single tax relief for caregivers of persons with disabilities. Unfortunately, the relief applies only to children caring for parents, not for siblings. This is an inequity that even our immediate geographical neighbours, Singapore and Thailand, have already addressed. This is the injustice that this study intends to rectify.

Whilst many prior studies have enunciated the problems faced by siblings of persons with disabilities, discussed the extent of their financial, psychological and emotional strains and attempted to interlink these issues, an obvious gap in the literature is that they provide only limited theoretical arguments and lack a substantive approach in making a case for sibling care tax relief. Hence, this study endeavours to bridge this gap.

#### **1.4. RESEARCH OBJECTIVE**

The primary objective of this study is to provide a vivid illustration of the problems faced by sibling caregivers and highlight the major issue of financial constraints, in spite of which there is motivation for a sibling to be a caregiver.

The study does not rest, however, on a simple understanding of sibling caregivers motivation but attempts as well to contribute to the existing literature by empirically examining the concept of accountability as viewed from the various perspectives. It draws on the principles enshrined in Vedic philosophy and views them through the lens of Schumacher.

In line with this objective, the fundamental aims of this study are to:

1. understand what motivates siblings to become caregivers.
2. develop a theoretical conceptualisation of accountability drawing from Vedic philosophy.

3. examine whether the caregiving motivation can be explained from an accountability perspective using the philosophy of Schumacher.
4. explore the state's role in supporting sibling caregivers.

This study contributes to the existing reservoir of theoretical knowledge involving accountability, theology, sibling care for persons with disabilities and tax relief in Malaysia by examining the interaction between these factors and further enhancing their contributory potential by utilising autoethnographic methodology, supported by the theoretical lens of Schumacher's philosophy.

### **1.5. RESEARCH QUESTION**

The research question serves as a guide to selecting the methodological approach that best addresses the research problem and accomplishes the research objectives. Answering the research question provides an understanding of the nature of sibling caregiving and how a person is motivated to provide caregiving to a sibling and the role of the State in supporting such a motivation. The answer to this question will be found through the examination of several sub-questions, including:

1. What motivates siblings to become caregivers?
2. What is an appropriate theoretical model of accountability to explain sibling caregiving?
3. Does the conceptualisation of accountability drawn from Vedic philosophy explain the motivation of sibling caregivers?

4. What is the role of the state in inculcating the concept of accountability in society?

## **1.6. METHODOLOGY AND RESEARCH DESIGN**

The methodology and research design used in this study are outlined in this section. The paradigm adopted is an interpretive perspective, the research approach is a qualitative study and the methodology employed is autoethnography.

### **1.6.1. Paradigm**

The paradigm selected was the interpretive perspective because this study aims to provide a deeper understanding of accountability of sibling caregivers and the Government to sibling caregivers, supported by Vedic principles and seen through the lens of Schumacher and prescribe an effective role to be played by the State. This study requires reflection on the lives of the sibling caregivers, their problems, pains and troubles. The irrelevance of other paradigms is evident in the remarks of Gaffikin (2006), who notes the absence of the human element and, in consequence, “self-reflection” in positivism, yet acknowledges its prominence in the critical realm.

### **1.6.2. Research Approach**

The predominance of the human element involves an interpretative and naturalistic approach encompassing personal experiences, life story interviews and expressions of feelings and emotions. These are obviously non-quantifiable and, as a consequence, necessitate the use of a qualitative approach.

### **1.6.3. Method**

The inspiration for the study arose from the researcher's own personal experience as a sibling caregiver. With the fundamental source of evidence being the researcher and his own story, no methodologies qualified for use except for autoethnography, where the "researcher" and the "researched" are one and the same. The researcher all at once becomes a part of the "family" or sub-culture under study, yet concurrently remains detached to perform his research duties.

This approach to research is not unusual: it has been endorsed by Doloriert & Sambrook (2011) who eloquently proclaim that autoethnography extends further than being a mere analytical writing style into being recognised as a modern avenue for evoking interpretivism. They are aware, however, of the resistance faced by autoethnography; the resistance is especially evident in post-graduate dissertations and theses where it faces the criticism of narcissism (Coffey, 1999), to the extent that some supervisors of these dissertations and theses discourage its use altogether (Morse, 2002). They also observe that the resistance is even more pronounced in business schools grounded on positivism and traditional methods of research as opposed to areas receptive to "contemporary ethnography approaches" exemplifying "social sciences, communications, health care, and illness" (p.584). Nevertheless they critically attempt to lift this dampening shroud of pessimism by encouraging the use of autoethnography as practicable research methodology by highlighting how it enhances the practice and serves to obliterate many challenges through the sharing of experiences (p.585).

The use of autoethnography is not new, as detailed by Doloriert & Sambrook (2009). They noted that it appears in research in many fields: "from anthropology (Okley & Callaway,



1992); sports sciences (Sparkes, 2000; Holt, 2003); nursing and health care (Ellis, 1993, 1998); to more niche contributions: design (Duncan, 2004); creative art (Ellis & Bochner, 2003); and political science (Burnier, 2006)” (p.28). Further in the field of higher education, they provide examples of “autoethnographies of early career lecturers (Holt, 2003; Pelias, 2003), senior academics (Sparkes, 2007), doctoral students (Humphreys, 2005), student-supervisor and supervisor-supervisor relationships (Sambrook et al., 2008), colleague related – relational ethics (Vickers, 2002; Medford, 2006; Ellis, 2007; Etherington, 2007), and research-areas-as-autoethnography (Ellis & Bochner, 2003, an autoethnography of writing a text book chapter on autoethnography); Wall (2006), ‘An autoethnography on learning about autoethnography’”(p.28).

In the field of accounting, we have Davie (2008), who provides classic arguments in support of the use of autoethnography as a methodological tool. She commences by acknowledging that accounting is no longer a subjective, dependant and technical subject devoid of the human element. Instead, it has now bloomed into a social reporting tool saturated with links to social phenomena and circumstances necessitating the need for a critical perspective of research. She explains that traditional “methodological themes and theoretical frameworks” have lost their relevance.” She continues to regret that not much has been done to provide real life anecdotes to illustrate these themes and frameworks (at p.1055) and further believes that the grain of “reflexivity” must be sown when undertaking research in a social science orientated discipline such as accounting. Therefore, where a study involves continuous exploration of “multiple realities” but requires the production of a consolidated interpretation and comprehension of the various information and accounts, the ultimate aim should be towards achieving a nexus “between the researched and the researcher(s)” (p.1072).

Davie (2008) recognises the construction of a theoretical framework as an “active, dialectical and continuous process” of examining and interpreting what is being observed and studied. This involves comparative efforts to recognise resemblances and clarify differences and ambiguities with an inordinate desire to “construct stories, themes, and linkages of (changes in) economic and social structures.” To this end, she concludes that the theory brings together the components of the subject being studied to contribute effectively to a reservoir of knowledge. Its achievement is mapped by the methodology (at p.1072).

She suggests that constructing a reservoir of knowledge, including initiating the process of knowing, with the aim of bridging “epistemology with ontological experiences” involves “theoretical, methodological and methodical choices.” This is because acquiring empirical evidence in a “social enquiry” entails an understanding of the “personality [,] ... background [and] biographies” of those participating in the research (Davie, 2008, p.1074).

In recognising that an excessive obsession with being objective in research (including ensuring that studies yield findings that are “value-free” and “bias-free”), stifles the research process and prevents “new knowledge from emerging” (at p.1074), she advocates that an autoethnographic study in accounting will lend support to enhancing our comprehension of “contextual experiences of producing knowledge and of the politics of academic capital” (Davie, 2008, p.1075).

The pursuit of knowledge is inspired and augmented when arguments about “what constitutes ‘something better’” arise, which is why researchers in the critical paradigm often welcome “honest intellectual disagreement”, recognising it as an asset in the process of acquiring knowledge (Thomas, 1993, as quoted by Davie, 2008).

However, an extensive search in refereed journals for the use of autoethnography in taxation did not produce any results.

#### **1.6.4. Research Design**

The design for an autoethnographic study commences with the researcher's own story. The researcher discloses his own skills in a story form where the readers can closely associate themselves in the fine details and immerse in the narrator's intimacy and feelings. The story allows readers to become part of the story rather than being an onlooker and involve themselves in the researcher's quandaries and predicament whilst joining him at every corner of decision making. (Ellis & Bochner, 2000, as cited by Wall, 2008).

However, to add an analytical component to the study, a search is made for "other family members". In the case of the current study, this endeavour was successful in identifying 17 qualifying sibling respondents who related their stories of caregiving for 18 persons. Therefore, a total of 17 in-depth interviews were conducted.

In a qualitative study, unlike a quantitative one, the number of respondents is not a criterion for evaluating validity and rigour. Research in social sciences, especially in the qualitative paradigm, has seen a notable evolvement in terms of both an "impressive growth of theoretical innovations" and the "conceptual revisions of epistemological and methodological approaches" (Noy, 2008, p. 327).

Noy (2008) also explains that sampling has been literally overlooked, qualifying as the least "sexy" facet of qualitative research, due to the fact that sampling procedures seem too

technical a matter for a paradigm in which scientific coordinates are the “poetic turn”, “negotiated texts” and “storytelling and narratives.” Or it might be because qualitative researchers employ sampling methods that are used in positivist-quantitative research, and therefore seemingly do not require reconceptualisation. In any case, the fact remains that sampling has been largely “left behind” the front lines of critical and deconstructive thought (p.328).

The irrelevance of numbers in qualitative research, especially in an autoethnography, is clearly illustrated in a conversation between a supervisor and her PhD student in Ellis (2007). The supervisor (Ellis) laughs at the pupil’s suggestion that 25 participants should be interviewed, and remarks that in conducting intensive interviews for autoethnography five or six, including the researcher’s own story, would suffice. However, she cautions that these interviews must be conducted on a platform of trust. She also explains that the researcher’s contribution to and involvement in evolving the interview proceedings will vary from interview to interview, depending on the degree of participation by the person being interviewed.

Therefore, in this study aside from my own story, interviews were conducted with seventeen participants and the researcher was able to recognise that a sufficient number had been achieved once the replies and answers started to become repetitive in terms of issues raised, explanations offered and reasons provided i.e. a level of saturation was being reached

Data collection commenced with a request for a semi-structured interview allowing taping, but with the absolute guarantee of anonymity. This was concurred to by a few, altered by some to “can interview but taping is not permitted”, and totally disagreed to by others.

However, for the last category, some were persuaded to complete the interview guide containing the same questions asked during the interviews.

#### **1.6.5. Emerging Themes**

The process began with transcription of the responses into Word documents, and uploading them to the NVivo software to facilitate coding of the transcripts. Using this software the researcher classified the words into identifiable themes as they emerged and interpreted the themes.

Darmody & Byrne (2006) commented that for software to be useful in a qualitative study it should enable data to be constantly accessible to facilitate assessment and evaluation for building a theory. Its features should transcend the provision of a mere description to being able to codify and categorise the data with a view to support the theoretical framework utilised in that study.

NVivo, a new generation of qualitative data analysis (QDA) software, is widely used and offers many new features to enrich qualitative analysis (Bazeley, 2002). In NVivo, inserting hyperlinks makes it easier and faster to jump to external data. Nodes represent ideas and may be linked to marked-up passages in documents if a coding approach to analysis is being used. Nodes may be organized into hierarchical trees (Crowley, Harre & Tagg, 2002).

## **1.7. RESEARCH MOTIVATION AND CONTRIBUTION**

The motivation for this study was the researcher's own experience as a caregiver for his sister. She was a paraplegic who, after having slowly come to terms with living with her paralysis, was hit again with the advent of cancer, to which she ultimately succumbed. Dealing with medical bills totalling thousands of Ringgit prompted the question by a fellow sibling as to why the Malaysian tax system provided no relief for all the expenditure incurred in caring for her. This clearly revealed a shortcoming in the Malaysian tax system and prompted the undertaking of this study to rectify the situation.

The motivation evolved from the concept of accountability, of a person to his or her disabled sibling, and of the government to persons with disabilities. Accountability itself is influenced by numerous factors, one of which is the spiritual outlook of a person undertaking the task of caregiving. Another factor is how the standards of governance advocated by the different religions are practiced by government. Since the realm of religious literature is too vast, a choice was made to start with the oldest religion, Hinduism, which was founded on the Vedic philosophy. An avenue utilised by the government to discharge its responsibility to its citizens is through the granting of tax relief, but the relief must benefit the intended recipient. Therefore, where persons with disabilities are not able to work and earn an income, the tax relief is worthless. However, the disabled need assistance from others, normally commencing with members of their own families. After the demise of their parents, and if the disabled are not married, siblings have to step in to provide caregiving.

There is no lack of literature in these areas in isolation, but no study has yet been undertaken involving a conceptualisation of accountability drawing from Vedic principles to evaluate the need for the introduction of tax relief for sibling caregivers. This provided the impetus for

undertaking the present study. However, a theoretical basis was needed to support the above opinion and the philosophy of the German-born English economist, Ernst F. Schumacher provided a suitable lens.

Although it would not benefit him any longer, the researcher knew that advocating for tax relief for sibling caregivers would provide an advantage to numerous Malaysians devoted to caring for their disabled siblings. Although it would be impossible for the government to provide tax relief equivalent to the amount spent on caregiving, even a small amount would nonetheless be appreciated by the sibling caregiver as a token of recognition of the services they had rendered. This would also bring about the harmonisation of the Malaysian tax system with that of our immediate neighbours, Singapore and Thailand, with respect to tax relief for sibling caregivers.

## **1.8. SIGNIFICANCE OF THE STUDY**

This study's foremost significance would be its theoretical contribution to addressing the literature gap relating to what motivates a person to become a sibling caregiver. In addition, this study goes beyond this by providing justification in the form of empirical evidence drawn from studies on accountability, and by taking principles enshrined in Vedic and Schumacher's philosophy. The relevance of the study has been further enhanced by adopting an autoethnographic approach, which has never been attempted before, at least in research in taxation. Finally, the study contributes to the harmonisation of fiscal policies amongst countries in this geographical region.

### **1.8.1. Abatement of Financial Burden**

As the literature reveals, the greatest challenge for the sibling caregiver is being able to pay for medical treatment, transportation, supporting equipment and health supplements required by the disabled sibling. Some form of compensation from the government would be appreciated by the sibling caregiver (Sainsbury, 1970; Blaxter, 1976; Hyman, 1977; Townsend, 1979; Martin & White, 1988; Grant, 1995; Burchardt, 2000; Gordon et al., 2000, as cited by Smith et al., 2004). See also Baldwin & Carlisle (1994), as cited by Smith et al. (2004).

### **1.8.2. A Recognition of the Sibling's Contribution**

Literature has also shown that sibling caregivers face numerous difficulties, make many sacrifices, and handle a great number of challenges in caring for disabled family members. Even if the tax relief does not equal the amount spent on the person with disabilities, it will at least serve as a motivator for them, and as an acknowledgment that government acknowledges and cares that the sibling has voluntarily assumed the responsibility of caring for the person with disabilities - a responsibility which is actually that of the government.

### **1.8.3. Harmonisation of Tax Laws in the Region**

The introduction of tax relief for sibling caregivers in Malaysia will synchronise the tax relief structure for sibling caregivers in the region between Malaysia, Singapore and Thailand.



## **1.9. STRUCTURE OF THE THESIS**

The discussion in this thesis is organised into eleven chapters.

### Chapter One: Overview of Research

This chapter discusses the background of the study, gaps in the literature on tax relief for sibling caregivers, the problem statement, the research question, methodology and research design, research motivation and the contribution and significance of the study.

### Chapter Two: A Review and Synthesis of Literature on Accountability

The chapter commences with a discussion of the concept of accountability and then focuses on accountability in accounting. It examines alternative views of accountability, including the religious perspective of accountability, moves on to look at accountability to society and then proceeds to provide a criticism of the practice of accountability.

### Chapter Three: A Review and Synthesis of Literature on Disability And Siblings

This chapter reviews the definition of persons with disabilities, Malaysia's stand on their status and the studies conducted on such persons. It then discusses the topic of siblings: the nature of their relationship, siblings as caregivers, their reaction when a family member becomes disabled and the trials and tribulations they face as caregivers. The discussion proceeds to look at factors that affect caregiving activity, the option of placing the disabled family member in a home or institution and the relevant government policies with regard to such issues.

#### Chapter Four: Sibling Disability And Caregiving: A Theological Perspective.

This chapter briefly reviews the religious stand on persons with disabilities, and the concept of caregiving from a Vedic and Hindu viewpoint. It also introduces the philosophy of Schumacher, which represents the theoretical lens for the evaluation of this study.

#### Chapter Five: The Role Of The State: Tax Relief for the Disabled and Caregivers

This chapter discusses the role of the State in discharging its responsibilities to caregivers of persons with disabilities. It advocates that one avenue would be to provide a tax relief to such people and therefore appraises the various tax reliefs currently available to persons with disabilities and to caregivers. It then compares the relief in Malaysia with that in our two immediate neighbours, Singapore and Thailand.

#### Chapter Six: Methodology

This chapter focuses on the theoretical perspectives in accounting research (the positivist, interpretative and the critical perspectives) to research and makes a case for the use of qualitative research as compared to quantitative research. It then evaluates the autoethnographic methodology, providing details of its benefits along with criticism.

#### Chapter Seven: Research Design

Commencing with a reflection on validity and reliability, the chapter discusses their relevance in an autoethnographic study, then moves on to data collection or capturing the salient experiences and ends with data analysis and interpretation.

### Chapter Eight: Stories: Mine & Other Sibling Caregivers

This chapter presents the story of my sister, her early life, the onset of her disability, her encounter with cancer and her ultimate demise. It also relates the individual stories of each of the respondents in this study. The respondents were generally caregiving siblings. The chapter also illustrates the motivation for undertaking this autoethnographic study.

### Chapter Nine: Emerging Themes

This chapter categorises the various emerging themes from the study to facilitate analysis and interpretation using the philosophy of Schumacher and the Vedas to illustrate the accountability of the State to sibling caregivers of persons with disabilities.

### Chapter Ten: Summary and Conclusion

In this last chapter, the contributions and limitations of this study are discussed, along with suggestions for future research.

## **1.10. CONCLUSION**

Chapter one provides an overview of the study illustrating how the lack of literature on sibling caregiving experience and understanding i.e. on why they do what they do has motivated the researcher to embark on this endeavour. Specifically, this study conceptualises accountability, draws on the philosophies enshrined in the Vedas and propounded by Schumacher and by employing an autoethnographic approach attempts to justify the introduction of such a relief. It ends with a discussion of the significance and contribution of this study. This next chapter discusses the concept of accountability.



## **CHAPTER 2**

### **A REVIEW AND SYNTHESIS OF LITERATURE ON ACCOUNTABILITY**

#### **2.1. INTRODUCTION**

Government accountability to society is the starting point to canvass for the introduction of tax relief for sibling caregivers. The purpose of this chapter is to review the extant literature on accountability and to identify research gaps. The discussion in this chapter is structured as follows: Section 2.2 deliberates on prior studies on the concepts of accountability. Section 2.3 views accountability in the practice of accounting. Section 2.4 discusses alternative views on how accountability is perceived and how it should be incorporated into the practice of accounting. Section 2.5 brings the discussion to focus on the religious perspective of accountability. Section 2.6 considers accountability to society. The discussion then turns to taxation, discussing accountability in taxation in Section 2.7, and then drawing a conclusion in Section 2.8.

#### **2.2. THE CONCEPTS OF ACCOUNTABILITY**

The meaning of the word accountability has been deliberated extensively by many scholars. Nelson et al. (2003, p.10) note the lack of clarity in determining the meaning and implications of accountability, but accept that it generally refers to “the obligation to give an account” (quoting Perks, 1993) and that it basically represents the reporting about the performance of one party, by that party, to another. Nevertheless, they recognise that a wave of evolution and considerable change has swept through accountability in the corporate world “as accounting

practices are reactive and develop mainly in response to changing needs at any given time” (p.10).

Axworthy (2005) explains that accountability answers the question of who reports to whom for what. He links accountability to responsibility and feels that to be responsible is to be answerable. Consequently, he surmises that answerability requires that an account be tendered to those to whom an account is due. This is further consolidated when he notes that Flinders (2001), in his study of the British Home Office, concludes that only an element of culpability represents the distinction between accountability and responsibility because the former is generally a report of the activities of illustrating an account of their activities and the manner in which they discharged their duties (p.3).

Jayasinghe & Soobaroyen (2009, p.997) explain that the “perceptions of accountability” have permeated accounting literature. They originate with a definition and interpretation of accountability by Sinclair (1995, p.219), embrace “debates in developing appropriate accountability mechanisms, principles and frameworks for non-profit organizations”, and culminate in studies relating to the formulation of “accountability characteristics” with Edwards & Hulmes (1995). In addition, Roberts, (1991, 1996) deliberates on “formal versus informal, and upward/vertical versus downward/horizontal”, while Jacobs & Walker (2004) reflect on “socialising versus individualising”, and Unerman & O’Dwyer (2006) consider “relational versus identity.”

Broad conceptualisations of what constitutes accountability are provided by many researchers (Arunachalam, 2011; Messner, 2009; McKernan & McPhail, 2012, etc.). These conceptualisations are summarised in Table 2.1.

Table 2.1 provides a rough sketch of the journey undertaken by accountability. From its humble beginnings of being a mere tool of giving account and practicing stewardship, accountability has progressed slowly to mean being accountable to society. Along the way it has assimilated components of moral values, fair and equitable judgment, of being dialectic and advocating social and environmental responsibility. However, the concept of accountability in isolation has no effect, and provides neither benefit nor advantage to anybody. The increased demands and obligations placed upon accountability require it to acquire a reliable tool for undertaking its new roles, integrating relevant information and disseminating the correct messages to the correct recipients. The most appropriate apparatus would be the practice of accounting, which is discussed in the next section

Table 2.1

## Concepts of Accountability

<b>Studies in social and environmental accounting literature . . . [which] generally agree that organisations are accountable to society at large for the impacts of their activities on the natural environment and society, and that accountability involves reporting to communities.</b>	<b>Cooper, 1992; Gray, 1992; Henderson, 1991; Lehman, 1995; Lehman, 1999; Maunders &amp; Burritt, 1991; Harte &amp; Owen 1987; Gray et al., 1996</b>
<b>Radical accountability in which the interests or values of the individual are subordinate to the interests or values of society.</b>	<b>Shearer, 2002</b>
<b>Giving an account is one means by which individuals are constituted as moral agents in communities and develop concern for the common good, human solidarity and basic respect...the development of new forms of ...accounting which have “enabling, empowering and emancipatory” (p. 365) potential to create a “fairer and more just society” (p. 365).</b>	<b>Schweiker, 1993; Bebbington, 1997</b>
<b>Fairness in accountability in the public sphere [means] that if there is more than one underlying set of values and assumptions in society, more than one should be given visibility during the reporting and deliberation processes.</b>	<b>Pallot, 1991</b>
<b>To rethink democratic accountability in terms of 360-degree accountability involves thinking in terms of webs of mutual responsibility and obligations that bind people in promoting the common good.</b>	<b>Behn, 2000</b>
<b>Explores the operational dynamics of 360-degree accountability under conditions of decentralised, collaborative and participatory policy making. Coalition...between citizens, government, regulators, businesses, environmentalists and other interested parties can produce accountability to a broad array of interests via informal institutions for decentralised, collaborative and participatory governance arrangements and policy making.</b>	<b>Weber, 2003</b>
<b>Communitarian model of accountability assumes the existence of accountability relationships in the public sphere involving the community, state and corporations [whereby] information is provided to the community on the environmental and social impacts of corporate activities.</b>	<b>Lehman, 1999</b>
<b>Conceptualise accountability as a dialectical activity involving answering, explaining and justifying by one party while those holding them to account engage in questioning, assessing and criticizing.</b>	<b>Aucion &amp; Heintzman, 2000; Bohman, 1996; Bovens, 2007; Mulgan, 2000</b>



Proponents of dialogic accounting [i.e. an] approach [which] emphasises the (a) development of accountability in the form of critical enquiry and dialogue between stakeholders and entities, [which is] (b) grounded in deliberative and agonistic models of democracy that incorporate critically reflective dialogue and effective participatory forms of decision making and accountability [with] (c) the aim...to facilitate pluralistic debates for evaluating alternative courses of action. [Therefore] in a broader sense, a democratic dialogue in the public sphere can be conceived as a form of accountability.	(a)Bebbington et al., 2007; (b)Brown, 2009; (c)Dillard & Roselander, 2011
Accountability is said to be a broader concept than stewardship...[a] form of principal agent [contractual] relationship. Accountee gives the power over resources along with instructions about actions and rewards to the Accountor . . . [who] is supposed to take certain actions and refrain from others in managing the resources given to him to meet certain objectives, and to account to his principal by giving information about his actions to him.	Hameed & Yaya, 2005
Differentiation between two forms of accountability: 1) hierarchical, whereby the type of accounting information and analysis should be “dictated by the categories supplied by accounting information”, and 2) socializing, which develops an awareness of the individual as a member of an ongoing community.	Roberts, 1996
To hold certain expectations about what this person or organization should be able and obliged to explain, justify and take responsibility for.	Cooper & Owen, 2007
Advocating social and environmental reporting practices.	Gray, 2002; Shearer, 2002; Unerman & Bennett, 2004
The idea of accountability has become ubiquitous in private and public contexts.	Munro & Mouritsen, 1996
The idea of accountability is notoriously difficult to pin-down.	Sinclair, 1995
Accountability involves “the giving and demanding of reasons for conduct.”	Roberts & Scapens, 1985
Various types, forms, and styles of accountability.	Ahrens, 1996
Practices of accountability have been employed to shape commitments, actions, and conceptions of the self.	Roberts, 1991; Willmott, 1996
The corporation as a moral agent.	Schweiker, 1993; Shearer, 2002
To be accountable for our activities we need both “to explicate the reasons for them and to supply the normative grounds whereby they may be ‘justified’.”	Giddens, 1984
Association of accountability with responsibility.	Bovens, 1998

Therefore, in summary, accounting commenced with a duty of transcribing, recording and reporting. It then acquired the status of being responsible and progressed to include values, morals and ethics in its practice. It stands today as a multi-faceted discipline incorporating economic, social and environmental factors in its reporting. However, accounting has a larger role than merely being a tool for reporting financial results. The conceptualisation of “accountability” in accounting includes a responsibility to account for many things, both quantitative and qualitative, with the latter referring to quality of life, the social and environmental impact of actions and corresponding reactions. The practice of accounting must uphold the very tenets of accountability to all stakeholders irrespective of power, politics or influence. It must be composed of objectivity, morality, integrity, fairness and equity.

Having concluded that an element of inadequacy prevails in the practice of accounting in relation to the discharge of its role as a tool for accountability, we now examine and evaluate the features, characteristics and perspectives that must be incorporated into the practice of accounting for it to be accepted as a vehicle for accountability.

### **2.3. CRITICISM OF ACCOUNTABILITY**

Gray (1992) clearly states that the concept of accountability is not spared of substantial criticism. This commences from Roberts & Scapens (1985), with aggressive arguments by Arrington (1990) and further comments by Roberts (1991). The general observation is that the process of accounting defines, mirrors, personifies, reinforces, and makes concrete the influential relationship between the preparer and the user of the accounts, implying that that it is an abhorrent activity saturated with oppressive and exploitative elements.

Another criticism arises from Tricker (1983) who argues that accountability emerges only when there is an enforceable legal right to be accounted to (i.e., the recipient of the accounts is legally entitled to receive them). Therefore, the preparers of the accounts only practice accountability in relation to obvious users and legal recipients of the accounting information. In more recent times, Messner (2009) has carefully evaluated the limitations of accountability. He commences his critique by classifying the notion that accounting should consider the impact of its reporting to every user of the accounts as definitely idealistic and unattainable. It is clearly impossible for the preparer of the accounts to recognise the needs of every stakeholder.

Against the backdrop of the classification of accounting by Roberts (2003) as an “expression of corporate egoism”, and also the argument of McKernan & MacLulich, (2004) of accounting’s “unjustifiable reduction of the other into sameness”, Messner (2009) lends support to the practice of accounting being standard- and quantity-based by arguing that it is a necessity in reducing the complexities of accounting, without which the whole accounting practice will fail. He argues further that in focusing on the needs of “the ‘other’ ultimately suggests that the ethical dimension of accountability is regarded in one direction alone”, and that this could lead to ignoring “the ethical significance of demanding an account” (p.924).

In presenting his criticism of accountability, Messner (2009) uses the work of Butler (2005), who cautions that the presentation of accounts equates to a narrative; transitions draw on a narrative voice, and are governed by an authority and structured to persuade the audience. He asks how one can justify a fair representation when many things are subject to the narrator’s ability to recall. Therefore, the failure to account accurately may not arise due to the preparer’s lack of responsibility but, instead, could have arisen

due to an incomplete comprehension of the events for which he might not be directly responsible and for which he has to rely on the rendering of an account by another. In line with this, she further argues that standard rules are necessary for the users to understand and acknowledge the narrative.

Based on Butler's (2005) text, Messner (2009) identifies three clear constraints to accountability. First, she recognises that in recalling events, experiences and occurrences, an element of opacity exists, inhibiting the ability to present a perfect account. The inherent inaccuracies are by no means attributable to a lack of responsibility but rather to a possible lapse of memory. Second, by being fully accountable to every user of the accounts, one is invariably burdening oneself with added responsibility, a task which the accountant may not be able to discharge reasonably under all circumstances and which, once undertaken, cannot be negotiated away. Third, accounting for all others places the preparer in a multi-faceted position, with each user of the accounts demanding a different form of information. Some even seek information beyond the economic frame, where the information has to be juggled with elements of values and judgment beyond the qualifications of the preparer of the accounts, thus placing the accountant in an unenviable position.

Shearer (2002) also concurs that provision of information beyond economic accountability poses a problem, whereas Roberts (2003) cautions that an ethical issue arises when the demand for information transgresses the limits of legitimacy.

Messner (2009) also explains that accountability to an audience comprising of people having differing agendas, as compared to preparing accounts based on a standard format or procedures, enhances the ethical burden of the accountant. She reiterates that

sometimes a conflict arises between the needs of different groups of users of the accounting information, and the accountant is forced to give more importance to one group over the others in discharging his responsibility. To provide an analogy, she compares the preparation of accounts for the profit-seeking shareholders to their preparation for a social and environmental group. This places the preparer in a difficult position of compromise, with the former group of users clamouring for maximisation of profits while the latter argues that the entity's contribution to sustainability efforts is insufficient.

Accountability to a series of new and varied "stakeholders" requiring information over and above that provided under the standardised practice of accounting, draws the preparer to an insecure region beyond that ensured by the walls of accounting standards, principles and practices (Butler, 2002; Foucault, 1997, as cited by Messner, 2009).

Based on the above, Messner (2009) justifies that a lack of accountability to every stakeholder may not be classified as being unethical because being accountable to all places an unachievable ethical burden on the accountant. However, Shearer (2002) maintains that although accommodating the needs of every user and meeting the requirements of every demand for information are not feasible, nevertheless improvements should be made instituted in the accountability systems to effectively reflect the responsibilities of both the preparer and the user of the accounts.

In essence, the criticism against accountability is that the degree of accountability is influenced by factors such as the degree of power and control that the accountee exerts over the accountant, whether the need to account to a particular user is enforceable by law, and whether a complete reflection of "the truth" could jeopardise the position of

more influential users. However, later literature reflects an acceptance of these banes of accountability, and that to be fully accountable to each and every user of the accounts is a utopian concept difficult at times to achieve. A unique account to satisfy the needs of every user necessitates standardisation beyond imagination. Further, an absolutely correct reflection of the accounts is humanly impossible due to the accountant's personal inadequacies. Problems may also arise from the conflicting objectives of stakeholders, which may ultimately affect the entity as a going concern. However, these problems rarely arise when evaluating the responsibility or accountability of a government towards society. With the concepts of accountability understood and the criticism against it having been clearly evaluated, we now look at the accountability of government to the society that it represents.

#### **2.4. ALTERNATIVE VIEWS ON ACCOUNTABILITY**

Many authors of accounting literature have moved on to a critical paradigm where the concept of accountability has evolved to a social and environmental platform perceiving socio-political and/or ethical issues involved and deliberating on how the practice of accounting under the capitalist economic system has impacted society and the environment (Messner, 2009). Recognising that the number and nature of the users of accounting information have expanded tremendously, he suggests that the current system of accounting should be sensitive to the interests and values of the new users. The needs of each stakeholder, however, may be competing although interdependent; the practice of accounting should therefore be strongly founded on ethical grounds so that accountability can achieve a harmonised and standardised platform (Saravanamuthu, 2004).

The practice of accounting should never be motivated by self-interest but, instead, should be driven with the equitable obligation to serve every relevant party in society (Peace, 2006). According to Shearer (2002), where self-interest prevails, it indicates ethical inadequacy. Krishnamurti (1991, 2000) explains that to be effective, accountability should mould itself to recognise the perceptions of each user of the accounting information because the same information is processed differently based on the experiential conditionings of each user. Accounting has been viewed as possessing an emancipatory power because it reveals and augments the development of social relationships made possible by the re-examination of information which is now available to a greater spectrum of stakeholders (Gray, 1992).

Further, Lehman (2004) explores the relationships between accounting, accountability, and religion in the modern world. He proposes that to solve the current ethical dilemma faced by accounting, we have to transcend the technical and procedural limitations of accounting practice and recognise its moral responsibility to society. Shearer (2002) also acknowledges that embarking on a social accounting journey necessitates fundamental changes to our accepted notions of accountability. The economic entity itself has to re-evaluate its relationship with the community within which it operates, and examine moral responsibilities and ethical considerations. Having recognised this expanded vision of accountability, the practice of accounting should be moulded to enable it to discharge the function of accountability effectively. Shearer consolidates her arguments using the thoughts of Schweiker (1993), who suggests that accountability starts with the acknowledgment of one's intrinsic interdependence with others in a community. Further, she supports Arrington & Francis (1993) who remark that the preparation of accounts provides an avenue for the economic entity to acknowledge the nexus between itself and the community by revealing the reasonableness of its actions.

However, the task of ensuring that accounting will be able to address all aspects of social, environmental and ethical issues through the establishment of much broader standards is thought to be utopian, with its achievement remaining on a sceptical plain: Roberts (1991, 1996, 2001, 2003) and McKernan & MacLulich (2004), as noted by Messner (2009).

The above discussion illustrates that accounting has a larger role to play than merely being a tool for reporting financial results: it has a responsibility to account for many things both quantitative and qualitative, the latter referring to quality of life, social and environmental impact of actions and corresponding reactions. The practice of accounting must uphold the very tenets of accountability to all stakeholders irrespective of power, politics or influence. It must compose of objectivity, morality, integrity, fairness and equity. The concept of accountability in accounting has been premised on the agency theorisation, emphasising maximisation of wealth for the shareholders, devoid of societal, cultural and moral values. The essence of accountability to society at large, where everyone is treated as a brother or sister, where there is love and affection for other living souls, and where individual profitability is forsaken for the universal good is clearly embedded in the tenets of theology and religion, which shall be examined in the next section.

## **2.5. RELIGIOUS PERSPECTIVE OF ACCOUNTABILITY**

This religious perspective of accountability has been widely recognised by scholars of accounting literature (McPhail et al., 2004; Lehman, 2004; Jayasinghe & Soobaroyen, 2009; Boyce et al., 2009; and many others). Walker (2006) states that even historically, a



clear link was established between accounting and religion. This has been perpetuated by both the influence of theology in the establishment of accounting concepts and practices, and by the influence of religious organisations on the economic and social lives of entities and people.

Studies to date have concerned Judeo-Christian churches, Buddhism and Islam. These have been featured in some of the contributions on “Theological Perspectives on Accounting” to a special issue of the Accounting, Auditing & Accountability Journal in 2004 (eds. McPhail, Gorringer and Gray), as well as on “Accounting and Religion in Historical Perspective”, in a special issue of Accounting History in 2006 (eds. Carmona & Ezzamel).

The practice of true social accounting (i.e., accounting that transcends the interests of people with a legally contractual relationship with the entity) could be achieved by importing moral imperatives from the Bible (Peace, 2006). Boyce et al. (2009) explain that “broadly put, beliefs and values matter in economic contexts because many religions represent or reflect ‘ingrained social values and beliefs’ (Daniels, 1998, p.969, as cited by Boyce et al., 2009, p.62) that are reflected in daily practices.”

Interpretations of notions of accounting, accountability and their associated practices are also fundamentally affected by the values and ways of thinking of those who do the interpreting. Thus, different “metaphysical” notions of the self, freedom and associated

concepts having socio-cultural and religious underpinnings are important in understanding accounting (Velayutham & Perera, 1996).

Lehman (2004) also explains that there is an inherent need for accounting practice to cultivate an identity saturated with values and perceived as a culture. Although operating within the confines of free markets, its notions of accountability should not be limited to instrumental procedures but, instead, be administered based on values respected by and associated with, a good society (which is normally ingrained in religious and spiritual practices). He therefore concludes that accounting should rise above its procedural standards and allow itself to be governed by religious values. Studies linking religious practice and accounting and accountability were mainly conducted from a Christian perspective but even that was confined to the “technical and functional perspectives of accounting” without an analytical interpretation of interaction of the practice of accounting with the philosophies of the religion (Jayasinghe & Soobaroyen, 2009, p.998). Lehman (2004) locks in the sheer importance of this perspective by commenting that the concept of accountability cannot divorce itself from religion by virtue of the fact that the moral values inherent in religion are an essential ingredient for accountability to develop.

Having looked at the various schools of thought on the subject of accountability, including the theological viewpoint, the existence of literature which critiques this concept of accountability is acknowledged in the next section.

## **2.6. ACCOUNTABILITY TO SOCIETY**

Social accounting involves evaluation of the problems facing society and the economy, and developing a solution for them (Boyce et al., 2009). Expanding from this, both social and environmental engagements make demands on the preparation and rendering of accounts, with different engagements having different levels of demand for accountability (Georgakopoulos & Thomson, 2008).

The Government is accountable to the people who voted it into power. It has already been established that it is government's responsibility to take care of persons with disabilities: it is part of their commitment, duty and obligation. Therefore, where a caregiver voluntarily takes care of his or her disabled brother or sister, the government has effectively delegated its duty and responsibility to that caregiver. Accordingly, just as a principal endows his agent with the necessary tools and equipment to undertake the delegated task effectively, the government must provide the caregiver with the resources (financial or otherwise), necessary to discharge his duties.

This supports the opinion of Georgakopoulos & Thomson (2008): where social reporting assumes an emancipatory role, it should embark on a detailed research of the engagement involved (e.g., in this study, sibling caregivers of persons with disabilities) and examine the relevant factors that constitute the accountability network. In this study, the endowment of tax relief is being researched as a dominant factor within the accountability web involving the government and society at large.

Currently, however, recognition in the form of tax relief is only given to caregivers who are parents or children of the person with the disability. This discrimination must cease

and the government must illustrate its accountability to society by endorsing the move to extend similar tax relief to sibling caregivers as well. Georgakopoulos & Thomson (2008) conclude that, in recognising practices in social reporting, the adoption of an all-inclusive approach is imperative; the granting of the tax relief should be universal and not instituted only for a privileged class of people. Furthermore, the conceptualisation of accountability has so far been discussed generally within the wide parameters of accounting. In the next section, the relationship of taxation to accounting will be evaluated.

## **2.7. ACCOUNTABILITY IN TAXATION**

Taxation constitutes a subset in the accounting universe. Although in essence a legal discipline in the form of Revenue Law, its position as an essential subject in the accounting curriculum is never challenged. The unique position of taxation can also be seen through the fact that it is an effective channel for government to achieve its accountability to society (OECD, 2008). This will be deliberated in the next section

The Organisation for Economic Co-Operation and Development (OECD), in its publication “Governance, Taxation And Accountability: Issues And Practices” (2008, p.3), reveals that studies have shown that the system of taxation not only serves to enhance the administrative capabilities but also promotes accountability. Taxation plays a significant role in moulding the relationship between government and the general public in terms of accountability and thus strengthens the capacity of the State. (OECD, 2008, p.13). Taxation is therefore a handy tool that can be used by government to

successfully facilitate any form of incentive and assistance to the public at large which, in essence, constitutes its social role. Further it facilitates the abatement of inequality in society through the redistribution of income (Zolt & Bird, 2005). However, the report questions the lack of attention given to firstly, how taxation supports the relationship between the State and its citizens and secondly the enhanced governance that can be reaped from a better implementation of the tax system and the manner in which taxes are collected (OECD, 2008, p.3). Also, where government is perceived to be accountable to society, resistance to increases in taxes will be abated (Zolt & Bird, 2005).

It is evident that there is a need to conceptualise accountability in the context of the State and its role in society. Given that the accountability concept cannot be divorced from religion, it may be appropriate to developing the accountability concept from the religious perspective. Such conceptualisation of accountability is limitless; hence this study has set the context to examine sibling caregivers.

## **2.8. CONCLUSION**

From the discussion above, it is obvious that accountability is ambiguous in its definition, abstract in its display, vague in its explanation but extremely wide in its application. In this chapter we have deliberated on what constitutes accountability, clarified the notion of “accounting” in accountability and considered the alternative view of accountability. We have reflected on the element of religion in accountability, recognised the limits of accountability and finally convinced ourselves of government’s accountability to society (in dealing with sibling caregivers in particular). One avenue

through which the state's accountability to society can be discharged effectively and with far reaching implications is through the use of the system of taxation.

Although accountability in the practice of accounting is narrow, the above review has provided an opportunity to pursue yet another route: to examine whether a conceptualisation of accountability can be used to explain the motivation of sibling caregivers, and to explore the role of the state in inculcating the accountability concept in society (which constitutes our third and final research question).The next chapter reviews and synthesises the literature on persons with disabilities and sibling caregivers.

## **CHAPTER 3**

### **DISABILITY AND SIBLINGS: A LITERATURE REVIEW**

#### **3.1. INTRODUCTION**

This chapter seeks to provide an insight into the literature pertaining to persons with disabilities, and siblings. With regard to the former, insight is provided with respect to who these people are, their rights both in the national and international arenas and the perception of the general public of a person with disabilities. With regard to the latter, insight is provided into their relationships, their reaction to the disability, and their trials in dealing with both the disability and the sibling with the disability. To start, it is necessary to consider what constitutes a disability.

Doessel & Williams (2011) explain that “there are numerous definitions of disability and/or handicap” as discussed, *inter alia*, by Annison et al. (1996), Cocks (1998) and Hahn (2004). They “recognise also that different conceptions and interests underlie these terminological disputes (Oliver, 1990).” However, disability is described in their study “as a reduction in health capital” where an abatement of day-to-day activities is evident both from a “market-based” viewpoint or otherwise. A handicap manifests itself first through “decreased earnings in a labour market” and again when the person with a disability needs “additional income” to sustain “the same standard of living as a non-disabled person” (Doessel & Williams, 2011).

Lobato, Faust & Spirito (1988), as quoted by Cuskelly (1999, p.226), developed a list of some of the ways the characteristics of disease or disability may differ:

- Onset (sudden/gradual).
- Aetiology (unknown/genetic/socio-cultural).
- Course or Phase (stable/fluctuating/improving/deteriorating).
- Prognosis (fatal/nonfatal).
- Visibility (physical appearance overtly affected/physical appearance not affected).
- Functional Implications (behavioural/cognitive/motor/multiple).

The remaining discussion in this chapter is organised as follows: Section 3.2 looks at the nature and status of persons with disabilities in Malaysia. Section 3.3 examines the role of siblings in caring for a person with disabilities. Next, Section 3.4 discusses the placement of the person with disabilities at a home or institution, while Section 3.5 deliberates on the trials and tribulations of a sibling caregiver. This is followed by Section 3.6 which reflects on the boons of caregiving and considers government policies. Finally, Section 3.7 concludes.

### **3.2. PERSONS WITH DISABILITIES**

Malaysia's commitment to better the lives of disabled persons is evident in the enactment of the *Persons with Disabilities Act 2008*, which was gazetted on 24 January 2008. The preamble of the *Act* clearly illustrates its objectives as an "Act to provide for the registration, protection, rehabilitation, development and wellbeing of persons with



disabilities, the establishment of the National Council for Persons with Disabilities, and for matters connected therewith:

- RECOGNISING that disability is an evolving concept and that disability results from the interaction between persons with disabilities and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with persons without disabilities:
- RECOGNISING the valued existing and potential contributions made by persons with disabilities to the overall wellbeing and diversity of the community and society:
- RECOGNISING the importance of accessibility to the physical, social, economic and cultural environment, to health and education and to information and communication, in enabling persons with disabilities to fully and effectively participate in society:
- RECOGNISING that persons with disabilities are entitled to equal opportunity and protection and assistance in all circumstances and subject only to such limitations, restrictions and the protection of rights as provided by the Federal Constitution:
- RECOGNISING the importance of the co-operation between the Government and the private sector and non-governmental organization in ensuring the full and effective participation and inclusion of persons with disabilities in society”

### **3.2.1. Who Are Persons With Disabilities?**

Section 2 of the *Persons with Disabilities Act 2008* defines persons with disabilities as those who have long term physical, mental, intellectual or sensory impairments which, in interaction with various barriers, may hinder their full and effective participation in society. The *Convention on the Rights of Persons with Disabilities* defines persons with disabilities as those who have long-term physical, mental, intellectual or sensory impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others.

In section 18 of the *Income Tax Act 1967 (as amended)*, a disabled person is defined as “any individual certified in writing by the Department of Social Welfare (JKM) to be a disabled person”. Recognition of a disabled person is through an identity card issued by the Department of Social Welfare. The Registrar for Persons with Disabilities shall issue a person who is registered as a person with a disability a “Kad OKU” [a special card for persons with disabilities]. A Kad OKU shall, unless proved to have been cancelled, be conclusive evidence for all purposes that the person has been duly registered as a person with disabilities under the *Act*. The Kad OKU shall be surrendered to the Registrar for Persons with Disabilities when a person ceases to be a disabled person.

In line with this commitment to assist persons with disabilities, Malaysia signed the instrument to ratify the *Convention on the Rights of Persons with Disabilities* on 6 July 2010.

### **3.2.2. Convention on the Rights of Persons with Disabilities**

The signing of the instrument to ratify the *Convention* by the then Minister of Women, Family and Community Development, Datuk Seri Shahrizat Abdul Jalil, showed the government’s commitment to protecting and improving the welfare of the disabled, women and children. The purpose of the *Convention* is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.

### **3.2.3. Studies on Persons with Disabilities**

Most studies dealing with the disabled deal with the person having the disability or handicap. The studies range from categories of “empirical or descriptive studies, and normative or prescriptive work” (Doessel & Williams, 2011). They recognise that there is an abundance of research studies in relation to the economic aspects of the disabled with documentation providing a constructive analysis empirically illustrating the reduced earnings of a person with disability as opposed to a person without any disabilities (Doessel & Williams, 2011). One such study, by Haveman & Wolfe (2000), explains the disability policy in general. Bradbury et al. (2001) relate severe disabilities (for Australia and Victoria) and various socio-economic variables (age, education, income etc.). Further, Brazenor (2002) vigorously estimates the earning equations for males and females, using demographic, economic and disability variables and draw upon Wilkins (2004) analysis of the effect of disability on four labour market outcomes, viz. labour force non-participation, unemployment, part-time and full-time employment. Similarly, Flateau et al. (2000) and Butterworth et al. (2004) analysed particular sources of disability viz. mental illness and contrasted their findings with Butterworth et al. (2004), Stern (1989), Baldwin & Johnson (1994), Hum & Simpson (1996) and Ettner (2000), that investigated similar concerns regarding the effect of disability on some labour force outcome or other.” At their own Australian doorstep were the studies undertaken by Cai (2003) and Cai & Gregory (2003, 2004) on the various analyses of the Disability Support Pension, a major income-support program for disabled people in Australia (Doessel & Williams, 2011).

As demonstrated, there is no dearth of studies on persons with disabilities, defining what a disability is, expressing what assistance needs to be provided, and what facilities have to be provided for them so as to ensure that they do not lose out on the joys of life. However, many studies on persons with disabilities have also gone off on a tangent with the objective of eradicating the compassionate take on disability. They have instead instituted an outlook of pride, adopting a positive view and demanding accountability to the disabled not on grounds of sympathy but as a moral commitment and a legal obligation, as discussed below.

#### **3.2.4. Alternative Views of Persons with Disabilities**

Reynolds (2012) advocates that society should change their outlook, commencing with shifting “away from seeing disability as a tragic flaw, the product of circumstances and bodies ‘gone wrong’”, including refraining from “referencing an individual’s impairment in terms of reduced ability and reduced personal fulfilment.” He advocates a positive view of persons with disabilities whereby society is able to see:

- a) beyond disability as a “problem” to be erased or done away with.
- b) beyond disability as something other than “us”, which then must subsequently be included according to an ideal of normalcy that is established by non-disabled people (often through ablest ideologies).
- c) beyond disability as something merely to be accommodated and “tolerated” and instead toward “genuine being with, not ‘doing for’ but receiving gifts from people with disabilities, who are valued as contributing parts of a shared communal life.”

In addition, Reynolds (2012) raises and adds “complexity to a view that signifies disability broadly”, as the World Health Organization (WHO) suggests:

*Disabilities are an umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations . . . Disability is thus . . . a complex phenomenon, reflecting the interaction between features of a person’s body and features of the society in which he or she lives. (World Health Organization, 2011, Health topics: Disabilities. Retrieved on 30 July 2012 from <http://www.who.int/topics/disabilities/en>).*

Betenbaugh & Procter-Smith (1998, p.281), as cited by Moberg (2008), classify persons with disabilities to include persons with a mental or physical disorder which is not easily rectifiable and which in consequence permits society to curtail the activities of that person. Eiesland (1994, p.27), as cited by Moberg (2008), differentiates impairment and disability / handicap explaining that the former constitutes “an abnormality or loss of a physiological form or function” whereas the latter, comprises “the inability to perform some task or activity that is or is considered to be necessary” in the case of a disability and “a social disadvantage” for handicap.

Reynolds (2012) refutes the claim disability can be aligned to vulnerability noting that the latter permeates unevenly through the human race with contributing factors being “...race, gender, class . . . locations and contexts . . . different religious contexts . . . rural or urban situations, and in various climates.” Therefore, he says “when seen in this light...disability is . . . a pervasive condition affecting everyone in varying degrees as they are subject to imperilment, suffering and/or violence that diminish human flourishing.” He concludes that “there is, in the end, no hard and fast line between

ability and disability, but rather a nexus of reciprocity that is based in our vulnerable humanity.”

In support of his view he quotes Moltmann (1998, p.10) who states that there is no difference between persons with and without disabilities. He believes that everyone has their own confines, susceptibilities and flaws but it is certain elements of our society that “condemn” certain persons as being “disabled.” On a similar note, Schumm & Stoltzfus (2007), cite Garland-Thompson (2005) who explains disability does not entail an element of being inferior, an illness requiring a cure nor an unattractive condition awaiting elimination but rather human existence in a varied form and culture.

This literature is rich and strong, and correctly portrays the thoughts of disabilities in a positive light. The disabled are equal members of society at large, entitled to their legal rights to equality. Their endowment should not stem from empathy but be the responsibility of the governing authorities. Thus, it is the moral obligation of the government, as the caretaker of society. to take care of them. This justifies the viewpoint of accountability from which this study emerges.

Having understood disability, considered the definition of persons with disabilities, and touched upon caregiving, the next section examines the contributions of siblings of persons with disabilities.

### **3.3. SIBLINGS**

A sibling is a term generally used to refer to a brother and sister, the relationship between two individuals with common parents, or simply a person who shares the same parents with another.

#### **3.3.1. Nature of Sibling Relationship**

An important aspect of the family system is the sibling relationship (Ali & Sarullah, 2010). A sibling is considered as one's first friend. In terms of family affiliation, the relationships of adult siblings are deemed the longest (Seltzer et al., 1997), are based on a common family life space (Ross & Dalton, 1981), and are egalitarian in nature (Avioli, 1989).

These relationships tend to be characterized by "supportiveness, concern and mutual affection" (Cicirelli, 1982). Sibling relations not only provide a reservoir of companionship, help, and emotional support, but also foster the acquisition of social and cognitive skills essential for healthy social development (Tsao et al., 2012).

The relationship between siblings is important (Brereton, 2011) and is only outranked in status by the bond between a parent and a child (Rivers & Stoneman, 2003). Brereton (2011) further highlights that the longest lasting family affiliation is between siblings because it cultivates "self-identity, social skills, companionship and mutual support".

It is obvious from the narrations above that sibling relationships have always been revered and placed on a respectable pedestal. However, an apparent question would be: would the potency of this bond weaken if one sibling is inflicted with a disability? Literature on this reveals that the onset of a disability on any member of a family impacts the family as a whole: the disability gives rise to emotions of shock, disappointment and sorrow. The flow of sympathy is, however, usually focused on the parents' struggle to cope with the disabled child, unintentionally ignoring the impact on the siblings (Turcic et al., 2004; Barbarin et al., 1995, as cited by Turcic et al., 2004). This weighs heavily on the siblings, who rarely discuss the issue with their parents but instead suffer privately (Sauer, 1984, as cited by Turcic et al., 2004).

In the next section the role of siblings as caregivers of persons with disabilities is discussed.

### **3.3.2. Siblings as Caregivers for Persons with Disabilities**

The demise of the parents of a disabled child naturally encourages the able siblings to provide support for their disabled sibling. The support eventually leads to taking on a fulltime caregiving role (Selwyn & Nandy, 2011; Roth et al., 2011). The caregiving role starts to blossom even during the lifetime of the parents, although studies show that the control and management of the disabled sibling is still vested with the parents (Seltzer et al., 1997). The able siblings learn to care for the disabled one in social and education endeavours, in sharing time with the parents and in generally providing peer support (Lobato et al., 1988).



Initially, there was a lack of studies involving the supporters or caregivers of persons with disabilities. This has been rectified in recent times as due recognition has come to be given to the contributions of siblings taking care of a person with a disability. In fact, a study was undertaken by the British Columbia Law Institute & the Canadian Centre for Elder Law urging authorities to institute law reforms in support of caregivers. Seltzer et al. (1997) opine that there is no lack of studies on parents being caregivers to their children but there is a dearth of research on siblings caregivers. Obviously the parents themselves may become incapable of providing care due to age or ailment or even death and inevitably the caregiving role will be inherited by a sibling which provides a critical necessity for studies to be undertaken on siblings as caregivers.

The reaction of siblings in facing and accepting the disability of a family member is discussed next.

### **3.3.3. Reaction of the Siblings in Facing the Disability of a Family Member**

Turcic et al. (2004) opine that the correlation between a person with disability and the adjustments made by their families varies depending on the conditions surrounding the family and the level of maturity exhibited by each member of the family. They enumerate these to include:

- feeling more pressure to succeed in sports or academia, or being concerned about their role in the future of their sibling with a disability (Coleman, 1990; Lobato, 1990; Powell & Gallagher, 1993).
- Siblings without disabilities may come to resent their unique siblings, as such a child may receive the largest amount of familial attention or be indulged or allowed to behave in ways that are not permissible to other family members (Bendor, 1990).

- Siblings without disabilities may feel guilty for having such resentments. They may also feel guilty for believing that they themselves caused the disability, or for being spared their sibling's fate (Koch-Hattem, 1986).
- An attempt to make sense of their sibling being born with a disability may prompt some siblings to engage in a spiritual journey (Cook, 1992).
- They may be faced with the challenge of arriving at some kind of resolution about their faith in order to effectively provide for the future of their sibling with a disability.

Having seen the potential reactive impact a person with a disability has on a sibling, we seek to understand what motivates siblings to undertake the caregiving responsibility.

#### **3.3.4. What Inspires Siblings to be Caregivers?**

A cursory perusal of the relevant literature reveals motivating factors stated in the preceding section: sibling affection, next closest kin after parents, “blood is thicker than water” mentality etc. The issue of siblings stepping into the caregiver role arises because many persons with disabilities live longer than their parents, who are their first carers/support providers (Dew et al., 2008).

A study undertaken by Griffiths & Unger (1994) reveals that siblings of persons with disabilities expressed their willingness to undertake the caregiving responsibilities upon the demise or infirmity of their parents. It also shows that a majority of both parents and siblings embrace the view that a person with disabilities should be cared for by his/her family, with the latter readily accepting the responsibility on a long-term basis. However, certain literature has commented on the influence of religion and a sense of duty, a vocation, or a calling as prime motivators for siblings to assume the caregiving role. These motivators are explored in the next section.

### *3.3.4.1. Religion*

The infliction of a disability is received with varied reaction and levels of acceptance and this, to some extent, has been attributed to a religious influence. Some persons with disabilities accept their infirmity calmly as the will of God (Turcic et al., 2004), whilst others lash out at the Almighty for inequitable cruelty. A similar reaction is anticipated from caregivers who, on one extreme, possess a composed preparedness to serve disabled kin while on the other, despise the burden bestowed upon them. In either scenario, a new way of life, a vocation, arises which historically has its roots in a religious context (Treadgold, 1999). This is also illustrated in the words of Aurobindo (1973), as quoted by Treadgold (1999, p.83) who suggests that everyone should follow the path of “dharma” as enshrined in the Bhagavad Gita, which prescribes that the motivation for one’s behaviour should not be “personal desire but [instead] divine spirit[,] working out its purposes through the individual.”

In the Christian faith as well, Treadgold (1999) comments that “people were called to live according to religious law, as evidenced by the scriptures.” He quotes from the Bible, from Corinthians, 7:24 which states: “Brethren, let every man, wherein he is called, therein abide with God.” However, Treadgold (1999), in recognising that religion is not the sole motivator for this undertaking, identifies the influence of a sense of duty as another factor, relying on the philosophy expounded by Freud.

The involvement of God in the infliction of a disability on a person has been commented on aggressively, not only from a negative perspective (with explanations that it constitutes a curse or retribution, as a “cross to bear”), but also with a positive

attitude whereby God uses disability as a means to illustrate His benevolence through the healing of the sick, as an opportunity for practicing charity or simply as a moral and spiritual lesson for those unafflicted with a disability (Reynolds, 2012).

The reactions of sibling caregivers of persons with disabilities have been studied with some results showing that they face colossal spiritual challenges, commencing with a revelation that a normal family life will never be enjoyed again (Turcic et al., 2004). The disability may spark a resentment of God for bestowing the disability on their sibling (Hogan, 1987, as cited by Turcic et al., 2004), or may lead to the questioning of God's justice (Kushner, 1981, as cited by Turcic et al., 2004). However, on the brighter side, some siblings derive comfort and relief from their religious conviction, their spiritual faith or just their basic philosophy of life, in facing the disability of kin or even grieving at their death (Kushner, 1981, as cited by Turcic et al., 2004).

Another study shows that the sprinkling of bliss and sorrow is generally prevalent throughout one's life and everyone actually harbours some form of disability (Schumm & Stoltzfus, 2007). However, the specific labelling of a person in line with his disability has been blamed on the medical system, which argues that this form of classification is necessary for revealing the results of a diagnosis. Such labelling, however, has adverse effects on the person with the disability who now wallows in self-pity and remorse, raising questions of why he was singled out by God to suffer this fate and which culminates in him equating his disability to spiritual deficiency

Although the influence of religion on the undertaking of a caregiver responsibility is clearly discussed in vast literature, another factor, a sense of duty, has also shown equal significance, as explained in the next section.

#### *3.3.4.2. Duty*

The influence of a sense of duty was discovered when respondents in a study of being caregivers expressed that the undertaking gave them a sense of happiness and satisfaction (Treadgold, 1999). The Freudian view is that the practicality of being engaged in a meaningful activity surpasses the transcendent gain. The ultimate objective is happiness and is not divine. As such, the undertaking should be motivated by the development of a healthy ego, an expression of a personal capacity for love and intimacy and not dominated by thoughts that one is born to do that job, or that it was a divine prescription (Freud, 1963, as quoted by Treadgold, 1999).

In linking this philosophy to siblings in a family, Treadgold (1999, p.85) cites Freud (1963) in asserting that the cohesive factor that binds a family is “work” (i.e., a sense of duty). The dispensing of this responsibility, he presumes, “offers . . . displacing a large amount of libidinal components”, endows “a value by no means second” to any others and classifies it “as something indispensable to the preservation and justification of existence in society” (Freud, 1963, Vol. 21, p.80).

In essence, the above narrative indicates that undertaking the caregiving responsibility gives the sibling work to do, cultivating in him a purpose for his life, which in turn

justifies his existence in society. After all, life itself is a gift, and throughout its journey many others bestow further gifts upon us, just as we endow them on others. Therefore, the demarcation between donor and recipient slowly evaporates, as should the distinction between an able and disabled person (Reynolds, 2012). Basically the above studies show that another take on sibling caregiving, aside from a religious commitment, exists: caretaking is undertaken with a sense of duty, and out of love and a sibling's affection. It is rewarding for the provider because he feels a sense of happiness and satisfaction. This provides an interesting alternative viewpoint.

The conclusion to be drawn from the above discussion is that the compulsion to care for a sibling with a disability stems from either a religious outlook (in anticipation of good blessings and benedictions in the hereafter), or from a sense of duty to take care of a fellow sibling. However, the study of siblings as caregivers would not be complete without a glance at the reasons why a person with a disability is not just placed in a home or institution. This will be looked at in the next section.

### **3.4. Placement in a Home or Institution**

Many people conceive that it is their responsibility to care for a disabled sibling throughout their life and disapprove of their placement at homes and institutions (Griffiths & Unger, 1994). A majority of the respondents in this study clearly indicated that upon their parents' inability to care for a disabled sibling, or upon their demise, they would continue caring for their sibling. The study also concluded positively that "almost half of the siblings reported that they would be willing to take on future caregiving responsibilities if their parents were no longer living or were physically

unable to care for the family members with [a disability].” This provides strong evidence that siblings of a person with disabilities prefer to take care of that person instead of placing them in an institution for disabled persons. Abundant literature supports this position; some of this literature is discussed briefly next.

The family bond is the principal factor in discouraging the placement of a sibling at a caregiving institution. The closeness between siblings, both physical and emotional, provides a sense of security (Remennick, 2001). In fact, growing up with a child with a disability instils in the others an accepted and taken for granted responsibility to care for the disabled sibling (Taylor et al., 2008). Therefore, naturally giving social emotional and practical support to a disabled sibling becomes part and parcel of family life (Dew et al., 2008).

In spite of the additional workload, the increased responsibility and the amplified stress which accompanies the decision to not place the person with a disability in a home, the caregiving responsibility is still adopted by the siblings. In fact, even though the responsibility of caring for a disabled sibling would mean the caregiver’s own children will have less of their parents’ time and the children will also have to sacrifice part of their parents’ resources time and energy (Welch et al., 2012), this has not been seen to be a deterrent. This is probably because the children see a closeness between their parent and the parent’s sibling and recognise within that relationship an ability to reciprocate, promote a mutual feeling and even efforts to negotiate and strategise (Welch et al., 2012).

The relationship between siblings has various impacts when one of them is disabled (Ali & Sarullah, 2010). These affect the way the family functions and also each sibling's nature, demands, and characteristics; a positive relationship is noticed where the time spent together is significant and is coupled with caregiving activities (Sharpe & Rossiter, 2002). Normally in the process of growing up this relationship will mature into a unique form where there is less equality, with the sibling who is able providing support both instrumentally and emotionally, and where both emotional and intimate closeness is affected because it is based more on caregiving rather than the sibling being a companion or mutual sharer (Taylor et al., 2008).

Normally a disabled sibling's stay in hospital has an adverse emotional impact on the other siblings. However, a study illustrates that the other siblings feel a sense of relief knowing that the disabled sibling is being treated and will be better soon (Houtzager et al., 2004).

On the part of the persons with disability itself, another study provides reasons for not wanting to be separated from one's family, which include fear of ill treatment from a foster family and concern that their rights to inherited property and land will be affected (Yanagisawaa et al., 2010).

The general perception is that the best support for persons with disabilities is the family (Seltzer et al., 1997). Upon the demise of the parents, the family should take on the responsibility of caregiving instead of placing the disabled sibling in an unsuitable institution. This is because the person with disabilities may have certain continuing



support needs which make them quite dependant, and he may feel rather vulnerable if placed in an institution which is not attentive to those needs (Dew et al., 2008). Further, placement at an institution is not cheap. Therefore, the alternative to institutional accommodation is for the able siblings to care for their disabled sibling and keep them at home.

However, caring for a disabled sibling is not an easy task: it frequently comes with problems of every nature, pressing the limits of insurmountability. The next section will address the issues faced by a sibling taking care of a person with disabilities.

### **3.5. Trials and Tribulations of a Sibling Caregiver**

Yanagisawaa et al. (2010) surmise that “sibling caregiving comprises four types of care: economic care, physical care, psychological care, and educational care.” They explain that economic care comprises the disbursements for “food . . . household expenditure . . . school fees for younger siblings.” Physical care entails “doing household chores and caring for young siblings as well as emergency care of ill siblings.” Psychological care involves “expressing love and care” and even assuming “the role of a ‘parent’ responsible for the cared for.” Last, educational care encompasses “training the cared for to assist in the daily care burden” and cultivating within them an ability “to be independent in the future” (p.123).

In line with this, we evaluate the problems faced by siblings caring for a person with disabilities. The difficulties are analysed under the broad classifications of

psychological effects, the impact that caregiving has on their daily lives, the sacrifices that they are forced to endure, the strain on their work commitments and, of paramount importance, the cost of caring for the disabled sibling.

### **3.5.1. The Psychological Effects**

Siblings that have grown up with a disabled brother or sister would have been exposed to the psychological effects and these effects would have evolved to some extent as they were growing up. The effect of a child's handicap is not limited to the child: all family members are affected (Fewell, 1986, as cited by Dyson, 1989). As siblings are usually intimately and intensely related (Dyson, 1989), the presence of a disabled child in the family will create a huge impact for the siblings.

Welch et al. (2012) illustrate the availability of abundant literature on the problems faced by these siblings: where the disabled sibling could be “disruptive or demanding or has violent or aggressive behaviour towards them” (Fisman et al., 2000; Floyd et al., 2009; Lobato et al., 1991; Williams, et al., 2010); how the siblings feel their lives are curtailed “by the need for the family to cater for their disabled children such that siblings miss out on enjoyable or developmental opportunities” (McHale & Gamble, 1989); whilst others “experience significant worry or concern about the wellbeing of their disabled sibling (Abrams, 2009; Gillies & Lucey, 2006; Guse & Harvey, 2010; Hames & Appleton, 2009). They go on to identify literature that shows that “children are forced to ‘grow-up too quickly’” (Abrams, 2009; Dyson, 2010; Schuntermann, 2007) and that the “siblings may experience stress, rage, shame or guilt in respect of their disabled brother or sister or aspects of their relationship with them” (Abrams,

2009; Findler & Vardi, 2009; Fisman, et al., 2000; Williams, et al., 2010). Also, that “siblings have been shown to develop very high or unrealistic expectations of their own behaviour or achievements, which may persist into adulthood” (Abrams, 2009), and that they are also “at increased risk of behavioural difficulties” (Fisman, et al., 2000; Verté et al., 2003). Houtzager et al. (2004) explain that being the sibling of a person with disabilities has an impact on their “daily routines, emotional state, social life, and, of course, family relations.”

Basically, we see a bitterness arising in the sibling for being deprived of a full childhood, complete with its pampering, doting, pranks and craziness. Also, anger at the induced acceleration to maturity, and annoyance with the placement of the burden of caregiving upon them even at a tender age.

However, studies also show that a compensatory element dominates the character of the non-disabled sibling, creating a desire to excel at all costs to please their parents and provide them with some comfort (Welch et al., 2012). Also, although it is clear that siblings of persons with disabilities experience psychological trauma and have difficulty adjusting their lives (Cuskelly, 1999), these trials prepare the siblings for the role of caregiver, which will be inherited from the parents upon their death or inability to care for the person with disabilities.

Upon assuming the caregiving role, the involvement in the act of caregiving sometimes pushes the sibling caregiver to regions of trauma and tension. Sometimes the stress of taking care of a disabled sibling can affect the health of the caregiver as well. Numerous

studies document a correlation “between stress and numerous physical disorders” (Clark & Watson, 1991; Folkman & Lazarus, 1984; Heller, 1991, as cited by Treadgold, 1999). Stress has been identified as a contributory factor in the development of “neuroses and even psychoses” (Kuiper & Olinger, 1989, as cited by Treadgold, 1999), whilst another common consequence of stress is depression (Gilbert, 1992 as cited by Treadgold, 1999).

In some cases, the task of caring for a person with disabilities far exceeds that of caring for an aged person. Remennick (2001, p.694) remarks “in terms of emotional burden, women who cared for the demented parents, were more desperate than those caring for the physically frail.” A respondent of his retorts that even the minimal hours that he spends with a mentally deranged mother-in-law make him feel that he himself is losing his sanity and he yearns “for the company of normal people . . .” (p.694).

These psychological effects remain with the caregiving sibling throughout his life. Although they are well concealed in most cases, they nevertheless affect the sibling and may at times expose themselves. Having looked at specific psychological impacts of caregiving, we now examine the effects on the life of caregiving sibling itself.

### **3.5.2 The Effect on the Sibling Caregiver’s Life**

Living with a disabled sibling has a strong effect on the life of any person (Seltzer et al., 1997), especially in terms of the able sibling’s constrained opportunities in relation to

the establishment of his own family (Taylor et al., 2008). The sibling may mean well in accepting the task of caregiving but in most cases he or she will have their own family (unless of course they remain unmarried).

As well, the magnanimous attitude of the sibling might not be shared by other family members and this might create some element of strain for the caregiving sibling. The level of acceptance by each member of the caregiver's family will vary because the presence of the disabled family member requiring special attention will present differing challenges to each member of the family (Ali & Sarullah, 2010).

Another problem is the attitude of the other members of the family who may feel that taking on the caregiving role has caused them to be neglected, or that time and energy that could have been spent on leisure activities or used to generate a higher income for the caregiver's family is being wasted (Remennick, 2001). Even the caregiver himself may feel the pinch of extravagance or the pangs of a lack of appreciation which slowly snowballs into a resentment of unachieved goals and a wasted life (Remennick, 2001).

The task of caregiving is not very easily delegated because the element of commitment, love and care is crucial in dispensing the duty entailed in the engagement. In many cases, other duties have to be taken on by other members of the family and this might not be happily accepted. Remennick (2001), who studied a group of immigrant women who assumed the role of caregivers informally to their parents, spouses and children [no difference is envisaged in the case of siblings], says "they usually paid for the technical chores, while the bulk of eldercare remained their own responsibility." A response received in that study clearly indicates that the respondent prefers to attend to her mother's needs personally rather than delegating them. She instead perhaps gets help with other household chores (p.694).

Aside from mental and psychological stress, Remennick (2001) also describes the physical strain on the caregiver's health, such as "chronic role strain, aggravated by some physically demanding tasks (e.g., turning and carrying bedridden elders) . . . gastrointestinal problems, back and joint pains, varicose veins, chronic fatigue and mood swings, and decreased immunity (manifest by high susceptibility to colds and other infections)."

A caregiver for a person with Asperger syndrome writes that undertaking the caregiving function "has meant 'letting go' of my own preconceived expectations about what human flourishing means, and instead learning to listen—and listen deeply—to the ways his own humanity requires affirmation, attending, and empowerment . . . [a] process has been disconcerting and painful, and has demanded patient and persistent practice . . . [and] . . . compelled adjusting my orientation in the world" (Reynolds 2012, p.34).

Consolidating their lives and their responsibilities to their own families with attending to the needs of a disabled sibling is no small task for the sibling caregiver (Krauss et al., 1996, as cited by Seltzer et al., 1997). The sacrifices made by a caregiver will be analysed next.

### **3.5.3. Sacrifices Made by Caregivers**

Sibling caregivers generally make great sacrifices. At a point in time after their own children have grown up and flown the coop and the moment of freedom has arrived where one can finally spend her time as she pleases, the duty of caring for a sibling with a disability annihilates the whole plan and she is back at square one. Many dream of

further education, fantasies of redecorating the house, ventures of gardening, imaginations of a perfect holiday and thoughts of just quiet moments with a life partner go up in smoke with this new undertaking.

Many disabled siblings need round the clock supervision for fear of both real and perceived danger; the caregiver's absence at any time must be substituted with the presence of another. One of the Remennick (2001, p.695) respondents speaks emotionally of how she struggled to help her son (who suffered a disability) to adjust to school life but felt relieved once he had "grown up and gone to the army" so that she could "start an advanced Hebrew class, learn painting (my long-term dream), travel around . . . " However, her mother became so fragile after an operation and had to be cared for, so her own life had to take a back seat again.

Remennick (2001, p.695) cautions that extensive caregiving chores can lead to "caregiver burnout syndrome", characterised by "chronic fatigue, depressive tendencies, somatisation, self-negligence and, in some cases, adherence to chemical means of relief (i.e., smoking and medical tranquilizers)."

The provision of caregiving in families burdened with symptoms of depression can have disparaging impact on the caregiver health especially mentally (Gitlin et al., 2003; Lopez et al., 2005, as cited by Lai, 2009), and this has been the concern of numerous researchers (Livingston et al., 1996, as cited by Lai, 2009). A person suffering from depression is highly dependent and in need of constant attention because they are prone to self-criticism and inducing self-guilt (Blatt, 2004, as cited by Lai, 2009).

Depression sets in when a person takes on the whole burden of caregiving upon himself without seeking assistance resulting in the relationship becoming strained and a lack of time for his own activities. This is further elevated if they have to observe the slow approaching death of their ward in cases of sickness which are terminal. (Cox, 1995, as cited by Lai, 2009). There is no denying that siblings assuming the role of a caregiver have to make sacrifices.

Having looked at the sacrifices being made, we now turn to the impact of caregiving activity on the work of the caregiver.

#### **3.5.4. The Effect on Caregivers' Work**

As seen in the preceding section, a caregiving function is not seasonal or something that can be planned in advance. This generally makes holding a full-time job almost impossible (Remennick, 2001). Thus, caregivers will need to be involved in jobs where they can either work from home and just deliver the finished product to collect their dues, or be remunerated only if and when they turn up for work. This is necessary in cases where the person with disabilities requires constant care and the principal caregivers can only excuse themselves when there is someone to relieve them.

Even with these kinds of job, a great deal of uncertainty clouds the events of each day. In their study of a group of women, Gorden et al. (2012) observed that caregivers that concurrently continued with their jobs faced relentless difficulties at work. The difficulties ranged from the inability to reach their workplace on time, through frequent disruptions at work, to regular applications for emergency leave.



Similarly, Bradbury et al. (2001) observe that having a disabled person in the family and the ensuing enhanced caring responsibilities curtails the prospects for or progress in, an employment because employers rarely understand the impact of the caregiving responsibilities. This may serve to cultivate a sense of resentment in the caregiver, although such is rarely expressed.

This has a domino effect in that the strain from increasing demands at work, coupled with the loss of opportunities, presents new challenges in both the attitude and behaviour of family members in discharging their caregiving duties (Gorden et al., 2012).

In many cases studies show that certain duties cannot be delegated even if the superiors, peers or subordinates are willing to help out (Gorden et al., 2012). Certain work functions require expertise which would have been the reason for appointment to that position. Unplanned absences and sudden disappearances from work will definitely have detrimental effects on job promotions, professional progress and career advancement.

Therefore, Gorden et al. (2012) state that the caregiver has to attempt to delegate his caregiving task rather than his work function. Obtaining either paid or unpaid help from others in the caregiving domain can create support for caregiving activities that cannot be created for work activities.

Poor performance at work will have an adverse impact on remuneration received, while the cost of undertaking the caregiver function would have accelerated upwards. This paradox will be discussed in the following section.

### **3.5.5. The Cost Factor**

The Joseph Rowntree Foundation of the United Kingdom undertakes research programmes and “innovative development projects which it hopes will be of value to policy makers, practitioners and service users”. One of these projects is entitled “Disabled People's Costs of Living”. The project was authored by Noel Smith, Sue Middleton, Kate Ashton-Brooks, Lynne Cox and Barbara Dobson with Lorna Reith. It was basically an inquiry to establish additional requirements of persons with disabilities including details of the related monetary expenses. This was necessary since it has never been denied that persons with disabilities do face additional costs to fulfil their basic needs but there is no evidential material on the exact quantum involved. A costing budget illustrative of these additional needs of persons with disabilities was developed in this research using a “rigorous consensual standard methodology”. Their findings have brought to light the additional costs relating to a person with disabilities. The findings have great relevance to this present research: where the person with disabilities is not earning, the cost of their needs is borne by the caregiver or another person that is supporting the caregiver.

Smith et al. (2004) explain that studies relating the financial burdens borne by persons with disabilities are not lacking (Sainsbury, 1970; Blaxter, 1976; Hyman, 1977; Townsend, 1979; Martin & White, 1988; Grant, 1995; Burchardt, 2000; Gordon et al., 2000, as cited by Smith et al., 2004). In addition, Baldwin and Carlisle (1994), as cited by Smith et al., 2004, discovered that the presence of a person with disability in a family generally relegates the family into poverty.

Doessel & Williams (2011), in quoting Sen (2004), explain that disability encompasses dual form of handicaps i.e. the ‘earnings handicap’ and the ‘conversion handicap’.” The first manifests itself because many persons with disabilities are either unemployed or work at jobs with inferior status and in consequence receive lower remuneration (Shaar & McCarthy, 1992). Their study also revealed that when persons with disabilities attempted to seek employment, they constantly meet obstacles and to overcome them they have to be from a family with connections with influential people, are financially sound and possess a status in that society which is illustrated by their sources of income, status through marriage and the house that they live in.

The second component of conversion handicap for persons with disabilities to perform the same task as non-disabled person, a higher source of income is necessary to effect payment for caregivers, purchase of wheelchairs or the installation of ramps. (Doessel & Williams, 2011, quoting Sen, 2004). Effectively they conclude that the inability of a person with disabilities to enjoy the same status of life as a non-disabled person with the same amount of remuneration constitutes the very essence of this handicap (Doessel & Williams, 2011, quoting Sen, 2004).

Many studies have tried to identify the additional costs incurred by persons with disabilities and, where they have no income, by their caregivers or their financial supporters. Wang et al.(2010) state that “the extra costs experienced...people with disabilities” commence with “the direct costs due to functional disabilities, such as the cost for treatment, special care, special services and aid devices.” These are followed by “the added cost of daily living specific to functional disabilities incurred as a result of unsuitable or discriminatory social service practices and policies, such as the cost of food, housing, transportation and communication, which may be higher than the cost for

people without functional disabilities.” Finally, there is “the opportunity cost, such as other family members’ income reduction due to supporting the older person.”

Berthoud (1991), in analysing the types of costs that are directly related to a person with disabilities (or his caregiver or financial supporter), identified the following four specific cost areas.

Firstly the basic needs of a person with disability are not very different from others but additional costs arise because of caregiving services, transport and extra fuel. Secondly, there are periodic costs compared with those that are one-off; the former encompasses expenses such as attire, nourishments and fuel whereas the latter include expenses such as special renovations needed or the acquisition of a more appropriate house. Thirdly, there are certain costs which are specifically incurred only by persons with disabilities such as caregiving, medical and transportation costs. Finally he details some negative costs whereby the costs are reduced for persons with disabilities exemplifying that a deaf person would not have the need for a radio etc.

The study by Morciano et al.(2012) concludes that “disabled people face higher costs of living than do non-disabled people” because “additional costs include the cost of adapting the home, overcoming the difficulties of getting about, and acquiring assistance with everyday tasks that non-disabled people can do unaided.”

Smith et al. (2004) suggest that standard of living of persons with disabilities is impaired due to several reasons. They identify the following examples:

- In terms of healthcare and welfare services, they explain that persons with disabilities have certain specific needs which are either not provided by the

statutory authorities or they have to wait for a very long time or its acquisition is a very challenging task (Large, 1991, as cited by Smith et al., 2004) and, as such, they usually acquire it at their own cost.

- Discrimination is also a contributory factor to the financial burden borne by the persons with disabilities. Indirectly it personifies itself for example as inaccessible modes of public transport resulting in the need to hire private transport, inability to enjoy banking services because of unavailability of braille or sign language guidance or simply not being able to take advantage of bargain sales due to the shops being non-disabled friendly. Charging additional life insurance premiums or insurance premiums for their cars and mortgage exemplifies direct discrimination (Lamb & Layzell, 1994, as cited by Smith et al., 2004).
- Persons with disabilities also suffer isolation in society. Based on the “Disability in Great Britain” report (Grundy et al., 1999, as cited by Smith et al., 2004), two-fifths of the persons with severe disabilities had not gone on any trips, enjoyed shopping nor visited their family members and friends in the month preceding the conduct of the interview. Although not denying that “inaccessibility of social venues” could be a contributory factor, Smith et al. (2004) nevertheless are confident that “the primary cause of social exclusion” is most “likely . . . insufficient income.”

Having considered the general areas of additional costs for persons with disabilities and their caregivers, we shall now look at the different types of costs discussed in the report by Smith et al. (2004).

#### *3.5.5.1. Personal Assistance*

The report reveals help with household task and chores is required. Depending on the nature of the disability, additional costs are bound to arise: laundry costs where excretory control is lacking, the cost of a maid or helper where the caregiver cannot manage to turn or bathe the disabled person, and paying for a substitute when the caregiver has to attend to his/her own matters. Where the disability involves hearing impairment, interpretation or communicational services may be needed. In the case of a seemingly sight deficiency, even cutting one’s fingernails may be a task for some disabled people.

#### *3.5.5.2. Food and Drink*

The nature of the disability may require the patient to take special food supplements or high protein or vitamin-saturated food or drink just to sustain their health (not as an additional booster). These products are usually expensive and tend to cut a deep hole in the pockets of the caregiver or the financial supporter.

The study by Smith et al. (2004) also illustrates the difficulty in bringing the person with disabilities outside the home for food, including ensuring that the intended destination is accessible to disabled person. As a result of such difficulty, food may have to be ordered for delivery to the home. This can end up being expensive. An example would be cost of celebrating a birthday at McDonald's, which is normally quite reasonable. If the disabled person is unable to go there, the food, drinks and the 'organised merriment' is imported to the house instead, entailing extra costs.

#### *3.5.5.3. Clothing and Footwear*

The durability of clothing and footwear is greatly diminished when used by a person whose disability forces excessive strain on them and brings about a higher rate of wear and tear. Extra cleaning or washing due to constant unavoidable soiling also contributes to diminished durability. Additional materials, such as mackintosh sheets, incontinence pads, diapers, etc. need to be used on an on-going basis when the disabled person has no control over their bowel or urinary functions.

#### *3.5.5.4. Housing*

Accommodation must be able to meet the needs of the person with disabilities. In many cases, adaptations or modifications have to be made to the home. A person in a wheelchair must be able to access the switches for lights, fan, air-conditioners and other electrical appliances. Toilet facilities may have to be modified to meet their needs. The television should be placed to facilitate viewing. The disabled person must have access to fresh air but the windows must have suitable latches so the person can open and close them on their own. In the case of a split-level or multi-storied building, additional modifications must be made to provide the disabled person with adequate access to all necessary places that they need to go. This may require the installation of a lift or, in the case of a wheelchair-bound person, they must be able to manoeuvre the wheelchair throughout the house with minimal assistance. All these alterations, modifications and renovations will incur costs, albeit not on a recurring basis.

#### *3.5.5.5. Household Goods*

Many special household items need to be purchased to accommodate a person with disabilities. For a person with limited mobility, a calling bell is essential. A visual indicator will be needed by someone with a hearing impairment, while a visually-impaired person would need a sound or vibration-based device to summon a caregiver in case of emergency. Sometimes additional safety devices and gadgets must be installed to facilitate the caregiving engagement.

#### *3.5.5.6. Transport*

A majority of caregivers suffer additional expenses for transporting their charges to hospitals, to homes of other relatives, to the park or other places. Normal taxis are costly and are sometimes hesitant to pick up a person with disabilities on the pretext that their entry to and exit from the vehicle will take too long. The vehicle itself must be suitable to transport the person with disabilities (e.g., there must be enough space to fit a wheelchair and the caregiver must also be able to follow).

#### *3.5.5.7. Recreation*

The person with disabilities is human and every effort should be made to make the person feel just like any other non-disabled person. Therefore, in addition to catering to their essential needs, their wish for recreation, and their desire to enjoy leisure outings should be entertained. This may, however, involve additional costs because non-chargeable alternatives (e.g., a visit to the park) are usually beyond the reach of the disabled because they are not either mobile or the place is inaccessible to them. Other venues may have stairways and no ramp for wheelchairs. Those facilities for person with disabilities are usually on the high end and are, in turn, financially too expensive.

The above illustrates the range of additional costs that a person may have to bear in undertaking the task of caregiving. Generally, voluntary behaviour intended to benefit other people or society as a whole is practiced by many, but it has been noted that the behaviour declines when related costs increase (Findler et al., 2005). Once one realises that the rewards from social activities do not match the high costs, i.e., that the costs



outweigh the advantages of prosocial behaviour, there is a tendency to refrain from such activities (Dovidio, 1984, as cited by Findler et al., 2005).

This clearly has a bearing on our research objective of discovering what motivates or demotivates sibling caregivers. Increasing costs discourage the undertaking of a caregiving responsibility. Government can remedy the situation by extending tax relief to caregivers of siblings to encourage them to assume the caregiving role upon the demise of the parents.

Although the trials and tribulations faced by sibling caregivers are numerous, an examination of various studies shows that a silver lining exists in every scenario. Tsao et.al. (2012) enlighten us as to the boons of caregiving: a person who perceived the positive attitude that his parents had of a disability borne by a sibling, and who had a good understanding of that disability, cultivated a strong sibling relationship (McHale et al., 1986, as cited by Tsao et al. 2012). Further, parents and teachers found that siblings of autistic children exhibited excellence in academic performance, had a good perception of themselves and exhibited healthy behavioural adjustment (Mates, 1990, as cited by Tsao et al., 2012). Persons with disabilities convey thoughtful and philosophical messages by reminding us of our vulnerability to misfortune, our susceptibility to calamity. They urge us not to be complacent behind the shield of a false sense of security (Vanier, 1998, as cited by Reynolds, 2012). However, this susceptibility is not only about injury or impairment but includes exposure to happiness, and contentment with what we are and what we have. It cultivates a bond between people, creating an atmosphere of shared dependency (Culp, 2010, as cited by Reynolds, 2012). Persons with disabilities have been known to assist with daily chores

at home in accordance with their abilities They take care of younger siblings, coordinate administrative tasks such as the filing of utility bills and calling for new gas cylinders, they take important phone messages and convey them accurately to the intended person, and they educate younger siblings and those with special skills. They have even put their skills to good use to generate some form of financial assistance for their caregivers.

Evidently, the sacrifices of the sibling caregivers can never be overrated; extra costs are incurred, psychological strains are endured and physical trauma is tolerated. Although the motivation for such endurance seems to come from the caregiver's religious outlook and their sense of civic duty (as evidenced by prior literature), one nevertheless cannot deny that the wider acceptance of this responsibility will come with a better understanding of accountability in society. As the accountability to society first and foremost falls on the shoulders of government, the role of the state is examined next.

### **3.6. SIBLING CARE AND THE ROLE OF THE STATE**

Government's failure to recognise the slew of problems faced by the caregivers of persons with disabilities by instituting remedial action is clearly evident in many studies. The sibling (kinship) caregivers face tremendous challenges. and are obviously in dire need of support. Their situation is further aggravated by the fact that they receive no privileges, enjoy no endowments and are not able to claim any funding from local authorities (Selwyn & Nandy, 2011).

The government's role extends further than merely providing facilities for the disabled at public places, allowing them to forego queuing up for an amenity, or giving incentives to companies employing disabled staff. It stretches to include the provision of all-enveloping support whereby the standard of living of a disabled person is equal to that of a non-disabled person. As seen from the previous discussion based on various identified literature, the major factor affecting caregivers is obviously financial.

Reynolds (2012) suggests that we should be “moving beyond disability as a problem to be fixed or cured, and instead considering it as one of the features of fragile human life that requires accommodation through the removal of barriers and/or providing resources for participation.” He reminds us that “disability invokes questions of accessibility and inclusion as a matter of justice and human dignity.” This in turn “necessitate(s) that personhood should neither be defined by nor reduced to disability as if it is something only and always negative.” Public policies should not be “ignoring it or trivializing” matters relating to persons with disabilities because “there is a real disadvantage experienced by [such] people. The authorities should therefore “addresses such disadvantage [by] accommodating [their] intended participation in activities deemed essential for a community's life together, both negatively by removing impediments and positively by furnishing with supplementary empowerments aimed at ensuring equity in opportunity.” This includes assisting caregivers whose objectives are in line with the above views.

### **3.6.1. Financial Problems of the Disabled / Caregivers**

Lai et al. (2009, p.443) comments that his finding emphasises how the financial element of accommodating the needs of both their own families and the persons that they care

for, within their constrained budget, has an immense psychological impact on the caregiver. Wang et al. (2010, p.81) recognises that “having a family member with a functional disability influences the living standard of the whole family [since] without support and on the same level of income, a family with an older person with a disability will have a lower living standard than a family without one because the interaction between functional disability and an inadequate service system causes the extra cost to fall on the household, leaving less money for other commodities and services.”

Berthoud (1991) explains that “looking at extra costs is particularly appropriate if we think about what would happen if disabled people were given extra income.” He argues that it should not be income that will be used for a necessity (something which even an able bodied person would require) because “disabled people pay them anyway, before they are offered the extra income.” Additional income must have the ability to “allow them to buy the other items which had been displaced by the specific disability-related expenditure.” These are not luxuries but instead “goods and services which were required only because the individual was disabled, but which did not take precedence over basic needs while income was short.” So now the disabled person can have the same living standard as a non-disabled person. Therefore, Wang et al. (2010, p.81) state “to reach the same living standard as that of a family without [a] person with a disability, a family would need additional income or support to cover the extra cost.”

Government action to ease the financial burden of the disabled and their caregivers, and the form of any assistance it provides, are the subject of the next section.

### **3.6.2. Formulation of Government Policies**

It is the duty of government to aid persons with disabilities, safeguard them from sustaining any deprivation due to their disability and contribute sufficient support so that they can live their life to the fullest in spite of their impairment. This will be achieved by ensuring they enjoy a living standard that is equivalent to that of a person without disabilities. Miles (2002b) expresses that “charitable provision is a duty of the state, and kindly concern is the duty of kings and their subjects.” The results of the study by Morciano et al.(2012) show that “the extra costs of disability are substantial, and rise with severity.” They recommend that “comparisons of the incomes of disabled and non-disabled older people must make adequate allowance for these costs if meaningful inferences about their relative living standards are to be drawn.” Therefore, Berthoud (1991) suggests that these additional costs of caring for the disabled should be borne by the Government so that the caregivers can use their own earned income on purchase their own needs just like others who are not caring for persons with disabilities.

Wang et al. (2010) complain that “without sufficient support to families of people caring for a person with a disability, the families bear most of the costs of disability”, and that the extra cost “has a financial impact on the living standards of [the]families . . . due to the extra costs of addressing the functional disability, leaving less money for purchase of commodities and services.” They note that this “has implications for social policy responsibilities because, without government support . . . people with disabilities and their families are more likely to experience poverty and social exclusion.” They regret that “the implications of the costs of disability have not attracted enough policy

attention in China” and add that “policy debates about the impact of the shortcomings of current disability support policies on the rights of . . . people with disabilities and their families remain a low government priority.”

Lai et al. (2009) “show the importance of programs and services that address the financial needs of family caregivers.” Their research reveals that “social workers, helping Chinese-Canadian family caregivers to establish a sound financial foundation to carry out their filial obligation is crucial.” To this end, they advocate that “income assistance or tax relief [and] social work interventions are needed to develop systemic measures” that will facilitate financial aid to persons with disabilities and their caregivers.

Therefore, the Morciano et al. (2012) study concludes that “disabled people experience significant additional costs as a consequence of their disability.” Government policy makers should give due recognition to this in the social security systems “through the provision of benefits designed to compensate for disability-related consumption costs.” They further advocate that “when carrying out analysis of the distributional impact of tax-benefit reforms, it is crucially important to make some allowance for these additional living costs, since failure to do so would give a misleadingly favourable view of the position of disabled people” (Hancock & Pudney, 2010, as cited by Morciano et al., 2012).

The above review of the literature clearly illustrates that a heavy burden is being placed on sibling caregivers. Whilst appreciating their dedication to provide care for a disabled sibling without placing them in an institution or a home, irrespective of their motivation,

we still need to recognise the problems they face, evaluate the obstacles they have to overcome and seek solutions to the difficulties they endure. The literature merely illuminates these problems; evidently a gap exists in terms of solutions. Therefore, to contribute to the literature, this study aims to empirically examine the need for the introduction of tax relief for sibling caregivers as a means of providing them with something of a reprieve. This solution is not new: it forms part of the fiscal policy of our immediate neighbours, Singapore and Thailand. Therefore, as an additional contribution, this study seeks the harmonisation of fiscal policies of countries in the region.

### **3.7. CONCLUSION**

In this chapter persons with disabilities and their siblings were examined; defining what constituted the former and discussing in detail matters relating to the latter. The intricate relationship between siblings and the role of siblings as caregivers to disabled brothers or sisters (including their reaction to the disability and their motivations in taking on the caregiving role) were analysed first. This was followed by an examination of the psychological, financial and emotional problems they faced. The chapter concludes by suggesting how the government could provide assistance to alleviate these difficulties. However, there is a lacuna in what motivates siblings to undertake the caregiving responsibility, and this constitutes our first research question.

In the next chapter a view on disability and caregiving from a religious perspective is provided.

## **CHAPTER 4**

### **SIBLING DISABILITY AND CAREGIVING: A THEOLOGICAL PERSPECTIVE**

#### **4.1. INTRODUCTION**

The association of theology with disability and caregiving is not uncommon. The *Journal of Religion, Disability and Health* ([www.tandfonline.com/toc/wrdh20/current](http://www.tandfonline.com/toc/wrdh20/current); accessed on 27/07/2012) has been in circulation since 1994. Known until 1999 as the *Journal of Religion, Disability and Rehabilitation*, the publication was initiated to meet the “growing awareness of the importance of spirituality and religion in health and human services”, and to address the “critical ethical, moral, and spiritual issues raised by people with disabilities in health and rehabilitation services.” In line with this, we shall now discuss disability and caregiving from a theological perspective. This introduction is followed by a general discussion on the support and comfort accorded by religion to persons with disabilities. As literature shows Hinduism and Judaism as being the origins of the other major religions, the third section observes the references made and doctrines established in relation to persons with disabilities in Hinduism. The fourth section introduces the lens of Schumacher, while the final section summarises the general principles observed in the earlier discussions.

#### **4.2. RELIGION DOES HELP**

Even from the dawn of time, the relationship between man and God is visible in every aspect of life, especially so in the case of persons with disabilities. Let us start with history.



#### **4.2.1. Historically**

Miles (2002c) notes that “the early records of history [show that even] when modern ‘missionary-sending’ nations were uncharted territory, societies of various sorts have made efforts to relieve disabled people.” He remarks that ancient “legal codes” and “prescriptions of religious duties” had made references to “disabled people.” In providing examples, Miles (2002c) states that “the idea of a metal prosthesis appears in the Rig Veda before 1000 BC”, whereas “in Athens of the 6th century BC, the Council awarded public pensions to blind people and later free food was given to people with other disabilities.” Finally “in Ceylon in the 4th century CE the Buddhist kings built refuges for physically disabled or blind people.” With this look at history we now move to the present.

#### **4.2.2. Impact on Persons with Disabilities**

The concept of religion is not just the mechanical performance of rituals and participation in ceremonies and festivals: it involves a whole communion with God. In describing the status of religiosity, Balasundaram (2007), whose study focused on mothers of children with mental handicaps, remarks, that for these mothers the “ideas of God and Faith had been something ingrained from childhood” and “their basic faith in rituals, as taught by their own mothers, had not changed.” She recognises however, “that their Faith had not become transformed into a deeper realisation of God, but remained a series of rituals performed at set times to set rules.”

Turcic et al., (2004), cite Pargament et al., (1990) when they declare “that a person’s religious beliefs are important mechanisms for coping during stressful situations and crises”, with a convincing note that “religion can also act as a basis for growth, hope and comfort.” They further consolidate their stand by citing Pargament et al. (1996) in stating that “a negative situation can be reframed in a positive light by its relation to one’s religious beliefs.”

Samuel (2009) remarks that “the logic behind shamatha (a Buddhist sense of a calming of the mind in Sanskrit) and analogous techniques is to calm and centre one’s consciousness to the point where it can begin to encounter the enormous and overwhelming complexities of reality... operate as a form of ‘stabilization,’ of building up a degree of calm, balance, and perhaps also of ontological security, as a basis for the encounters that lie ahead.”

Schumm & Stoltzfus (2007), cite Frank (1995), who “views illness and disability as a part of a person’s life journey and as an opportunity for moral and spiritual development [which] affects relations with others, shifting from egocentric self-pity to greater responsibility and care.”

So does religion also affect the function of caregiving? This question will be examined in the next section.

#### **4.2.3. The Influence on Caregiving**

Universally, all religions prescribe that aid and assistance should be rendered to the needy, disabled, sick, the aged and children unable to fend for themselves. Miles (2002c) writes that “in all the well-known religions and philosophies...there have been at one time or another some sympathies and enlightened work with disabled people.” This involved “relieving the sufferings of disabled people, whether by care, or by changing social practices so that they did not need ‘care’ but could live a life with some dignity by their own efforts.”

Balasundaram (2007) aptly describes that, for the caregivers of person with disabilities, “the intensity of their belief had changed in varying degrees according to the difficulties they had faced. There is still “active involvement in organized religion [and] they continued to perform rituals”, but they had abandoned hope that their prayers would be answered – although some still kept a window of hope open for miracles to happen (Balasundaram, 2007).

Generally such predicaments encourage “the search for meaning” whereby the caregiver transcends their resentment to the Lord and starts to develop a profound comprehension of the presence of the disability within a religious framework realising that caring for them is a challenge in their life as opposed to viewing it as an evil infliction by God. (Turcic et al., 2004)

Findler et al. (2005) observe that “religious individuals claim to be more responsive than the secular to the needs of others and therefore can be expected to provide more help and to be more engaged in charitable deeds.” They further conclude that since adherence to religious principles generally teaches that “charity should be offered to anyone in need” therefore, “similarity should not be an important factor in determining prosocial behaviour.”

The profound affection for the person with disabilities and the caregiver’s sincere objective of providing caregiving “alone seems to give them a reason to carry on the struggle irrespective of whatever problems they may face” (Balasundaram, 2007). Philosophically she concludes “after all, how many of us can say with Paul, in 2 Corinthians 1: 8-9, speaking of the hardships he had suffered, ‘We were under great pressure, far beyond our ability to endure, so that we despaired even of life . . . But this happened that we might not rely on ourselves but on God’” (Balasundaram, 2007).

However, just as every good thing has a polluting and jeopardising agent out to destroy its virtue, religious principles, beliefs and philosophies have not been spared.

#### **4.2.4. Wrongly Perceived and Contorted Religious Views**

Otieno (2009) notes from a Kenyan experience that “the lives of persons with disability continue to be marked by experiences of discrimination, prejudice, and inequality . . . [for example] . . . employment practices tend to favour people without disabilities [which in turn] . . . inhibits the ability of persons with disability to become productive

members of the society.” She remarks that “one of the major root causes for the discriminatory acts against persons with disability in Kenya is religion-related [because] theological interpretations of disability have significantly shaped the ways in which society relates to persons with disability.”

She is saddened by the fact that oppressive interpretation of The Bible and related texts has served “to reinforce the marginalization and exclusion of persons with disability in the social, economic, political, and religious life of the society” as evidenced by “the experiences recounted by persons with disability.” She quotes Eiesland (1994, pp. 73-74) “[who] identifies three theological themes that have created obstacles for persons with disability.”

She commences with the view of “conflating disability with sin”, leading to “the belief that disability indicates punishment for wrongdoing and mars the divine image in humans [and this] has often barred those with disabilities from positions of leadership or stigmatised them for their presumed lack of faith.” She then moves to the second theme, where disability “[is seen] as virtuous suffering”, which is perceived “as suffering that must be endured in order to purify the righteous, a teaching that encourages passive acceptance of social barriers for the sake of obedience to God.” She culminates with the view that persons with disabilities represent “cases of charity.” While charity is generally good, in this case it “subverts justice when it segregates persons with disability from society and keeps them out of the public eye rather than empowering them for full social, economic, and political participation.”

Schumm & Stoltzfus (2007), cite Garland-Thompson (2005), who lament that persons with disabilities “carry not only some form of physical disability, but they often also

carry a spiritual burden resulting from a religious and social milieu that is suspicious of their spiritual condition”, with the “persistent insinuation that chronic illness and disability somehow involve merited suffering (i.e., lesson to learn or result of sin).”

Miles (2002c) claims that the true measure of greatness in a society is the quality of care for its weakest members. He therefore advocates that “this is also a good question to ask of a religion or ideology, i.e., how it addresses itself to disabled people and deals with problems of disablement; or the even more searching question of whether the adherents of that religion or ideology are in practice motivated to care for disabled people, to lend them strength and to receive from them what they would offer.”

The above discussion draws strength from a religious perspective. However, the existence of numerous religions serves at times to confuse devotees, but this is very simply overcome by emphasising the similarities and commonalities between the various religions (Kelkar & Vaishnav, 2001). They advocate the coexistence of all religions because religion stands a beacon of spirituality essential for providing guidance to the human race in these materialistic times. The mutuality in religions can be attributed to the fact that most religions descend from two ancient ones: Hinduism and Judaism (Kelkar & Vaishnav, 2001).

In view of the above, examining the viewpoints of all of the major religions would tantamount to a duplication of efforts. The examination will therefore be restricted to the discussion of the teachings of Hinduism in relation to disability and caregiving, as literature has shown Hinduism to be the oldest religion.

### **4.3. HINDUISM**

Balasundaram (2007) traces the pattern of involvement in religion when she notes that when faced “with no awareness or information” on the disability at hand, “they (the family of the person with disability) increased observance of traditional and familiar rituals and increased visits to places of worship.” However, as the severity of the “disability and...problems” increased, “their faith dimmed” and they viewed “their poverty, their financial insecurity and alcoholic husbands as punishments” – as part of their Karma. This plunged them into “a paradoxical situation” because now “since it was [their] Karma, [they] could not blame God for it” (Balasundaram, 2007). So what is this concept of Karma?

#### **4.3.1. Karma**

Gupta (2011) states that “although the law of karma originated in Vedic Hinduism, eastern religions . . . such as Buddhism, Jainism, and Sikhism, also believe in it in one form or another.” Karma is widely understood to be analogous to the principle of ‘action-reaction’ in physics whereby “all of our actions are conditioned (causality) and have consequences (effects)” (Schumm & Stoltzfus, 2007). The general rule of Karma is that all actions (both good and bad) that we perform in this life will have consequences and repercussions either in this life itself, or in the next. This explains the need for reincarnation, where the soul enters into a new body to settle the accounts for its past deeds (Gupta, 2011).

However, others have perceived the endurance of a disability (or any problem or difficulty for that matter) not as a consequence of past deeds, but instead as an avenue to appreciate the kind assistance of others, to recognise true affection, love and care as provided by a caregiver, or basically to be saved from the traumas experienced by many able-bodied persons (Miles, 2002c).

This leads to the discussion of Karma and Disability in the next section.

#### **4.3.2. Karma and Disability**

The link of Karmic philosophy to disability is validated because “a person’s misfortune may be the result of bad deeds (bad karma), done in the present or the past life” (Yamney, 2004; Dasgupta, 1968). Miles (2002a) connects the meaning of disability to “misfortunes, sent by deity, fate, karma; often associated with parental or personal sin, as in the Laws of Manu (XI, 53):

*Thus in consequence of a remnant of (the guilt of former) crimes, are born idiots, dumb, blind, deaf and deformed men, who are (all) despised by the virtuous. (Bühler, 1886, 440)*

The infliction of a disability is not random but is instead the direct result of either a sin committed by an individual in this life, or by what the soul had done in a previous life (Miles, 2002a). The individual has no one to blame but himself, not any judge and definitely not God (Schumm & Stoltzfus, 2007). Without the principle of Karma, every infliction of disability or unfortunate experience will be attributed to God and would lead to a rapid deterioration in devotional activity and faith and belief (Gupta, 2011).



Doniger & Smith (1991, p. 256), as cited by Miles (2002a) “see in Manu’s prescriptions an elaborate ‘dance of the victims and the victimizers’, in which those who have killed other creatures in past lives become fair game for the ‘social death’ of disability in their present life.” “The Institutes of Vishnu list disabilities and the sinful state in a previous incarnation, giving rise to them[;] one who steals a lamp will be blind; a usurer will be epileptic; one who consumes dainties alone (not sharing) will be rheumatic” (Jolly, 1880, pp. 147-49, as quoted by Miles, 2002a).

Viewed from a different perspective, the endurance of a disability could well be a means of attaining enlightenment, rather than being a form of retribution. For example, an arrogant person’s misdemeanours could be neutralised by the infliction of a mental handicap in order to harness and eradicate his arrogance, thereby enabling the soul to merge with the Divine (Miles, 2002a).

Miles (2002b) states that “religious beliefs have been associated [with disability], at many times and places.” He enumerates “a number of essentially ‘negative’ views, which may see a disabling impairment being given as a punishment, inescapable consequence or statistically probable consequence.” He elaborates further that it may be a “casual (not necessarily causal) outcome of different permutations of persons, actions and lives”, as categorized below:

<b>(a) disabled people’s own</b> <b>(b) their parents’</b> <b>(c) their society’s</b> <b>(d) humankind’s</b>	<b>(i) sinful actions</b> <b>(ii) ignorance and foolish actions</b> <b>(iii) accidental actions</b> <b>(iv) mistaken beliefs</b>	<b>(w) in the present life</b> <b>(x) in a previous existence</b> <b>(y) in earlier centuries</b> <b>(z) since the human race began</b>
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However, persons with disabilities should take this in stride, knowing that nothing happens without the approval of God, and recognising that the affliction is merely a sharp bend in the soul's journey to achieve enlightenment and that the soul remains absolutely divorced from the inadequacies of the human body (Gupta 2011).

Miles (2002b) also subsequently offers an alternative “positive” view of disability from a religious perspective, as detailed below, which he says has “come under strong attack in recent decades from Western disabled people groups and they may be rejected very bitterly by some individuals in almost any country.” This alternative positive view contends that disability is:

- 1. an open-ended challenge for the strengthening of a person's soul.**
- 2. a specific lesson to be learnt, to enable the soul to make progress.**
- 3. a challenge to the disabled person's family or other carers.**
- 4. an opportunity for the deity's power or love to be demonstrated.**
- 5. an opportunity for individual or neighbourhood charitable action.**

However, at times this principle of Karma can be distorted to the extent that every person with a disability is frowned upon for having to pay his dues for past sins. This may result in adverse implications for the person and his family (Gupta, 2011).

On the bright side, knowledge of the principle of Karma empowers a person with disabilities to recognise his past misdemeanour(s), accept his current fate and smile that his ‘sins’ are being wiped out by his suffering. It gives him hope that the future is not bleak, that his existence has meaning and it encourages him to seek to learn self-improvement techniques (Sharma, 1999, as cited by Gupta, 2011).

Gupta (2011) extols the benefits of comprehending Karma because it serves to give meaning to one's life, helping one to take control of it, and even undertake a transformation. Karma is adaptive, in that it makes suffering endured by a person more bearable (Miles, 2005). This is exemplified by survivors of an earthquake (Priya, 2002), and the faster psychological recovery of victims of disabling accidents (Dalal & Pande, 1988). In fact, studies involving religious coping amongst Hindus has shown that the theme of Karma is a permeating link (Tarakeshwar & Pargament, 2001).

Having looked at the relation of Karma to disability, we now examine Karma and caregiving.

#### **4.3.3. Karma and Caregiving**

The understanding required here is that the disability is divorced from the person: the person is not impaired in any way but rather his body has a part which does not perform its intended function effectively. Unfortunately, the environment is not conducive enough to accommodate such ineffectiveness, thus the person suffers (Miles, 2002a). An optimistic view of this dilemma, however, is that it presents an opportunity for the other members of the family to provide assistance and, in consequence, earn good Karma (Gupta, 2011).

Gupta (2011) explains that "The Bhagavad Gita [the Holy Book for the Hindus] promotes forbearance, patience, and endurance", and teaches that "a man is urged to strive for equanimity in happiness and unhappiness, pleasure and pain, heat and cold and success and failure (Bhagavad Gita 6:7, 12:13; 18). In line with this scripture, any

forms of pain, distress or agony are buried internally in the person bearing the sorrow, and with minimal revelation to the general public, in the staunch belief the Lord wanted it to be this way as a result of the person's sins in his past lives (Gupta, 2011).

Gupta (2011) quotes from The Bhagavad Gita, which "prescribes acceptance of pain and suffering as the will of God", which states that "the Lord saves those who depend exclusively on Him for redemption, from the ocean of mortality" (Bhagavad Gita, 12:6; 12:7), and which promises that "the Lord absolves one who surrenders unequivocally to Him, from all sins (Bhagavad Gita, 18:66)."

The principles enshrined in The Bhagavad Gita assist persons with disabilities "in accepting and resigning to the predicament." However, this acceptance "does not mean passivity"; it facilitates the "acceptance of failure to restore 'normalcy' despite efforts" (Gupta, 2011). This is clearly illustrated when the Book reveals "you are free to perform actions but are not free to control their results. Therefore, perform actions without attachment to their results" (Bhagavad Gita, 1: 47).

However, the discussion would not be complete without reviewing literature that rejects the notion that caregiving is influenced by religion and evaluating its veracity.

#### **4.4. BUT SOMETIMES IT'S NOT RELIGION!**

Miles (2002c) relates that “one day I was surprised to learn that a person whom I respected for her compassionate but non-patronising good relations with the residents was not a believer in any recognisable deity...her strength was greater than mine, but she did not acknowledge the same source, or any particular source.”

Findler et al. (2005) opine that the willingness to help others, which is basically referred to as “prosocial behaviour”, is performed “even in the absence of conspicuous external rewards [because] helping others may still be personally beneficial, incurring self-awards such as positive self-feedback for being kind and caring, or precluding self-censure, guilt and shame.” Neglecting a disabled sibling may be frowned upon by society; therefore the task of caregiving might be “voluntarily” undertaken.

Findler et al. (2005) also illustrate that “dispositional or personal correlates of prosocial behavior include adherence to the norm of social responsibility, self-esteem, empathy, levels of moral development, autonomy, religiosity, and social desirability.”

However, even in these opposing opinions, with Miles (2002c) attributing the urge to assist others as arising from the compassionate nature of the caregiver, and Findler et al. (2005) accrediting the voluntary disposition to society's outlook, it is obvious that the very foundation of any religion is based on compassion, love, sharing and caring. Therefore, the theological contribution is evident, although not vividly displayed, through the profession of any standard religion per se.

Having concluded the analysis and discussion of the influence of religion on caregiving and the disabled, we review the values, beliefs and essence of Schumacher's philosophy which serves as a theoretical lens for this study.

#### **4.5. THE LENS OF SCHUMACHER'S PHILOSOPHY**

The theoretical support for this study is further enhanced by viewing its essence through the lens of the philosophy propounded by a German-born English economist, Ernst F. Schumacher (1911-1977).

Schumacher has been described a "one of the strongest opponents of conventional economics in his time . . . [who] . . . outlined a coherent alternative view on almost all the most striking economic problems of today's world" (Zsolnai, 1993). Schumacher is an economist-philosopher, a progressive entrepreneur and an early twentieth century prophet of the current ecological crisis. Although a talented academic, he became frustrated by theorising and so became a practical exponent of his theories on business, agriculture and journalism (Varma, 2003).

Two of his famous books are *Small is Beautiful: A Study of Economics as if People Mattered*, and *A Guide for the Perplexed*. The philosophy expounded in these books is the foundation for justifying the endeavour of this study because the essence of Schumacher's philosophy is that it is centred and focused on the human factor. The single human is a comparatively small as opposed to the environment, corporate entities, nature etc., hence, Schumacher's advocacy for "small is beautiful." The general themes established in *Small is Beautiful* were summarised by Wade (1975,

pp.199-200), and are detailed below to illustrate how they support this study's advocacy for sibling tax relief.

First, Schumacher scoffs at the illusion that modern economies have solved the problem of production because production depends heavily on natural capital such as air, water, and resources which are depleting at a geometric rate. He urges the development of a new lifestyle designed for permanence. In the same light, since government has delegated its duty to provide for persons with disabilities to the families of the disabled, it should give due recognition to the individual problems faced by these families (including siblings) as they in essence are undertaking a duty of government. Neglecting the sorrows and difficulties of caregivers will cause problems for the government if the caregivers decide to abdicate their roles.

The second theme propagates Schumacher's opinion that innovations in science and technology should be re-orientated so they can be used by everyone with minimal destructive and disruptive effects on mankind. The relevance of the theme to this study is that showering relief on persons with disabilities serves no purpose if they have no income to absorb the relief. The granting of the relief should be purposeful, i.e., it should be granted to those supporting disabled siblings.

Third, Schumacher advocates the principles of Buddhist economics which, amongst other things seeks to maximize human satisfaction by the optimal pattern of consumption. Similarly, the government should concentrate on enhancing the wellbeing of the man on the street, understand the day-to-day problems that they face, appreciate the sacrifices made by such people and not be concerned only with macro factors of gross national income, investments and the general progress of the nation.

Fourth, he promulgates the need to knead the dough of science and technology with the essence of human values, moral awareness and ethics. Just as education untempered by wisdom is merely a means without an end, similarly progress from a technological viewpoint should be able to withstand the test of human satisfaction and wellbeing from every aspect. In the same vein, although government has given various forms and amounts of tax relief to persons with disabilities, such relief is worthless if they cannot use it because they have no income. The same argument can be made with respect to relief for parents and children of the disabled, as the literature reveals numerous cases where the parents are no longer generating income or are deceased, and the person himself has no children. What, then, is the worth of the relief for such a person?

Extending the thought from the fourth theme above, Schumacher's fifth is that certain activities require the human touch, irrespective of the extent of technological advancement. There is a general perception that technological advancement translates into economic progress for the people, serving to uplift the wellbeing of the people. This is not, however, without exceptions. The caregivers of the disabled have a 24/7 job and no amount of technological progress can replace the human factor in the caregiving process. This provides an excellent argument to pursue further extended tax relief for caregivers to include those bearing the financial burden of this caregiving activity.

Schumacher's final theme is that progress should be universal, enjoyed by everyone, and something that permeates through and nourishes every person in society. However, he laments that in many cases, so-called progress, advancement and innovation have thrust the poor into further poverty because the "progress" is focused on urban areas, ignoring residents at the outskirts and in rural areas. Schumacher advocates the creation of cheap workplaces located in various areas, instead of being concentrated in urban



domains. This would permit accessibility to all and encourage production technologies that use local materials and easily acquired skills to facilitate greater participation of people from all walks of life. Similarly, it is apparent that the non-recognition of the sacrifices made and problems faced by siblings of the disabled has pushed this category of people backward, especially in terms of financial prosperity. This is an issue requiring urgent addressing by the stewards of public policy.

#### **4.6. CONCLUSION**

To sum up, the study commenced with a conceptualisation of accountability and the recognition that accountability is not just the activity of rendering an account but involves being accountable to every affected party and to society at large (especially by the government). Then, the universal conceptualisation was precipitated to focus on persons with disabilities. The principles from Vedic philosophy were then examined to justify the need for such accountability. Finally, accountability was viewed through the ‘small is beautiful’ lens of Schumacher, who emphasises the importance of the individual and advocates a revamp in government priorities (which tend to focus on the macro level of providing incentives to further the interests of big companies, but ignore the needs of the man on the street).

The chapter provides an insight into the principles enshrined in Vedic philosophy in relation to disability. This assisted in explaining the motivation of sibling caregivers mentioned in the first and third research questions. The chapter also explains the philosophy of Schumacher, which provides a theoretical lens for the second research

question of what is an appropriate theoretical model of accountability to explain sibling caregiving.

With the conclusion of the visualisation of, and deliberation and reflection on, the interconnection and interrelationship between religion and persons with disabilities and the undertaking of a caregiving responsibility, the next chapter provides a discussion on the tax system in Malaysia. Specifically, the tax system's relevance to persons with disabilities and their caregivers is examined, particularly in terms of tax relief available to sibling caregivers. A comparative review of such relief available in the other countries is provided.

## **CHAPTER 5**

### **THE ROLE OF THE STATE: TAX RELIEF FOR THE DISABLED AND CAREGIVERS**

#### **5.1. INTRODUCTION**

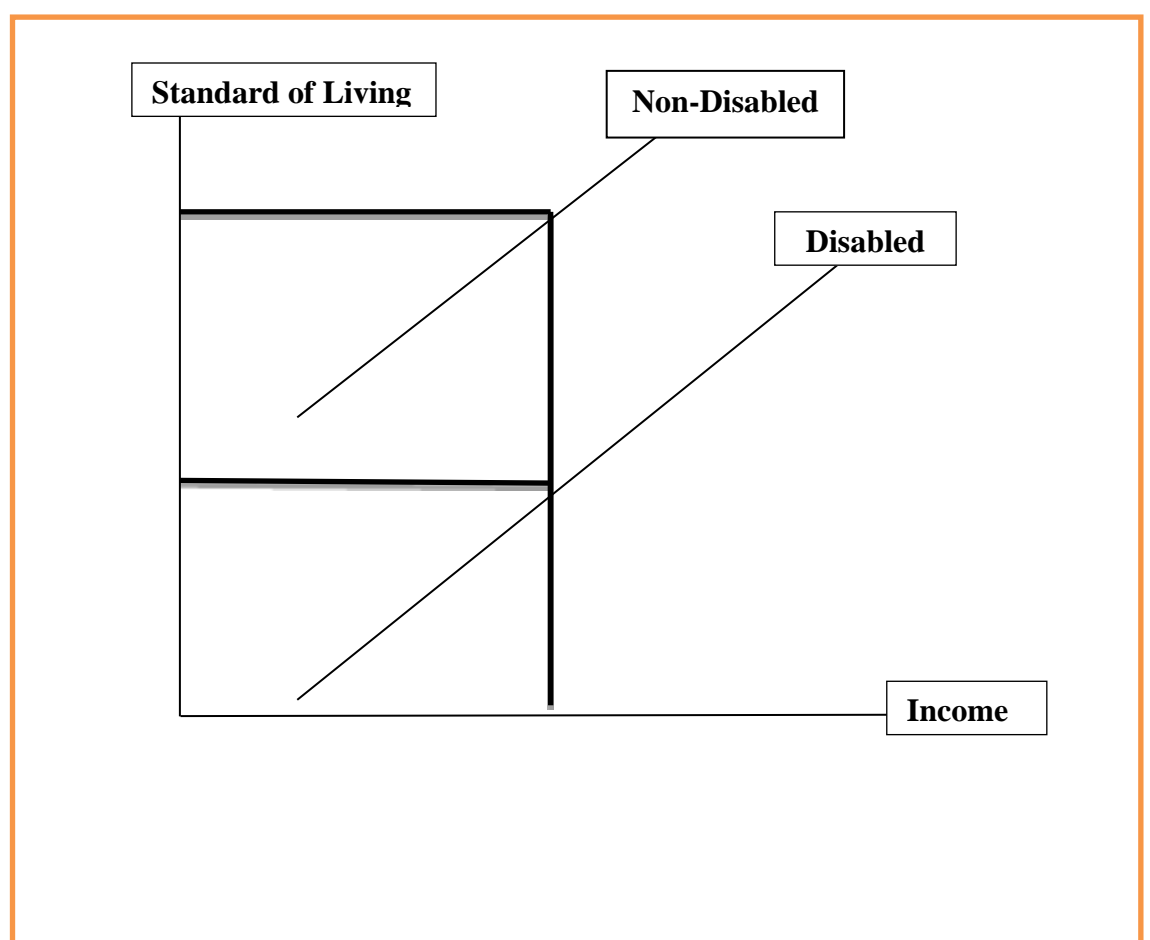
Having understood the religious perspective on persons with disabilities and on caregivers, literature relevant to addressing the last research objective of exploring the state's role is reviewed. One of the main avenues for the government to discharge its accountability to society is the field of taxation. As one of the governing principles in taxation is equity and fairness, the chapter begins with a discussion of justice through taxation. This is followed by a look at government policies, followed by an evaluation of current tax relief for and incentives in respect of, persons with disabilities. Next, support and tax relief for caregivers in Malaysia are reviewed, and compared to that offered to sibling caregivers in Singapore and Thailand. The chapter is summed up with conclusions.

#### **5.2. JUSTICE THROUGH TAXATION**

Doessel & Williams (2011), in advocating that the fundamental of social justice prevailing in modern society has now been extended to and installed as a goal in, the field of taxation, explain that this is illustrated by ensuring that all persons are treated equitably in the administration of tax laws. They reiterate that the feature of "equality" is an essential ingredient not only in the introduction of taxation but also in its administration (Mill, 1861, as cited by Doessel & Williams, 2011).

They illustrate this using the study of Berthoud (1991) which “outlines how three different and relevant phenomena i.e., the standard of living, income and disability, can be conceptually related” and depicted visually with the aid of a graph as shown in Figure 5.1.

Figure 5.1  
The relationship between income, standard of living and disability



Although Figure 5.1 clearly illustrates that although there is a direct relationship between the income and living standards of a person but nevertheless at all levels of income the standard of a person with disabilities lies below that of an able-bodied person. (Doessel & Williams, 2011). This serves to demonstrate the concept of “conversion handicap” propounded by Sen (2004) i.e. that keeping the level of income

constant, the disabled person enjoys a standard of living below that of an abled-bodied person (Doessel & Williams, 2011).

Doessel & Williams (2011) also offer an alternative way of considering Figure 5.1 by asking what income the person with disabilities must earn in order to enjoy the same standard of living as his able-bodied counterpart. Based on the assumption that a particular standard of living is necessary, the “income” of a person with disabilities should be supplemented to achieve a level sufficient to provide him with the required standard of living. Wang et al. (2010) clarify that for the family of a caregiver of a person with disabilities to have the same standard of living as that of a family with no persons with disabilities, the family would “need extra income or services to cover the disability related costs.”

Johns & Green (2009) further highlight the importance of equality by demonstrating a latent nexus between equality and discrimination. They hold that “the theory is that if everyone is treated equally then there is no room for discretion and it is through the exercise of discretion that discrimination occurs.”

Wang et al. (2010), in agreeing, feel that “a social perspective of disability views disability as exclusion from mainstream society experienced by people with impairments as a result of prejudice and discrimination, at cultural, social and institutional levels.” To rectify this, they propose that “support services and financial support to address the costs of disability” be furnished to these persons with disabilities, because if “the additional costs of disability fall entirely on the person or the family” it would have “a profound impact on living standard.”

This argument of equality and justice for the disabled spills over to the caregivers as well, especially when the person with the disabilities has no source of income and all expenses and related costs are borne by the caregiver. Undertaking the responsibility of caregiving whilst also managing their own families obviously results in an enhanced financial burden which translates to a lower standard of living. So how can this inequity be addressed? Amongst the numerous avenues available, this study looks at the tax system to provide a reprieve. As the fiscal system is almost always vested in the hands of government, a look at government policies is in order.

### **5.3. THE STATE'S ROLE IN TAXATION**

Doessel & Williams (2011) recognise that “Government policy can alleviate inequities in living standards . . . through the disbursement of ‘grants to disabled people’.” This is further supported by Miles (2002), who indicated that “there is a growing interest . . . and a desire to assist in shaping policies for disabled people” by those who “widely believe that appropriate policies can be implemented only if there is some positive change in public attitudes toward disabled people.”

Having established the primary role that government can play in assisting persons with disabilities, we narrow the focus to explore the ways this can be achieved through taxation.

Nolan (2006) notes that in designing benefits and reliefs in taxation to facilitate the equitable distribution of income, the influential factor has always been the “work-life balance goals”

In line with this we shall now look at the tax relief that the Malaysian government has provided for those who need assistance i.e. the aged, disabled and abandoned children.

#### **5.4. CURRENT TAX RELIEF AND INCENTIVES IN MALAYSIA**

For decades, the Malaysian government has used the tax system to provide financial assistance to persons with special needs, such as the disabled and those who support them. In illustrating its commitment to ease the financial burden of disabled persons, the government has incorporated numerous tax reliefs in its tax legislation, especially in the *Income Tax Act 1967 (as amended)*, hereinafter referred to as “the Act”. These are discussed below.

##### **5.4.1. Existing Tax Relief for Persons with Disabilities under the Act**

Tax relief is basically accorded to a taxpayer as a deduction from his total income in ascertaining his chargeable income. The different types of reliefs granted with regards to persons with disabilities are detailed below.

###### *5.4.1.1. Disabled Individual [Section 46(1)(e)]*

Currently, relief of RM9,000 may be claimed by every individual for the basis year (year of assessment). A disabled person, however, can claim an additional RM6,000 and their relief claim would total RM15,000. This additional relief is available to both the husband and the wife in the case of the filing of separate assessments.

#### *5.4.1.2. Disabled Spouse [Section 47(1)(b) and Section 45A]*

An individual can claim spouse relief of RM3,000 in the year of assessment for either a husband (Section 45A) or a wife (Section 47), provided that the couple are living together in the year of assessment. The concept of living together is not a geographical concept but one of intention: they must not be divorced or separated by an order of a court, a deed of separation or a written separation agreement. In addition, a further RM 3,500 may be claimed if the spouse is disabled, for a total claim of RM6,500.

#### *5.4.1.3. Basic Supporting Equipment [Section 46(1)(d)]*

A maximum claim of RM5,000 can be made in the year of assessment for the purchase of any necessary basic equipment for use by a disabled individual or his spouse, child or parents.

#### *5.4.1.4. Disabled Child [Section 48(1)(d) and 48(2)(b)]*

The parent of a disabled child may claim child relief of RM5,000 as opposed to the relief of only RM1,000 that may be claimed for a non-disabled child. In addition, if the disabled child is receiving full-time instruction at any university, college or other similar educational establishment, or is serving under articles or indentures with a view to qualifying in a trade or profession, the parent is entitled to claim increased relief of RM4,000. This brings the total claim for a disabled child to RM9,000

A child is defined as a legitimate child, a step-child of the husband or wife, or an adopted child provided the Director-General is satisfied that the adoption is in accordance with any law (not necessarily Malaysian law). With effect from the year of assessment 1996, a wife living together with her husband and who is assessed separately



on her income, may elect in writing to claim child relief. To claim child relief, the child should be unmarried, maintained by the claimant and the child's total income for the year of assessment must not exceed the amount child relief claimed.

#### *5.4.1.5. Medical Expenses for Parents [Section 46(1)(c)]*

Initially this sub-section provided relief only for medical expenses incurred in respect of a parent; a proposal in the 2011 Budget served to include special needs and carer expenses as well. However, the carer could not be the individual himself, his spouse or child. Other eligibility requirements specified that the parents should be Malaysian residents, the medical treatment and care services should be provided in Malaysia and the medical practitioner should be registered with the Malaysian Medical Council.

The government's recognition that some individuals had special needs and required the services of a carer was at least a step forward. It also provides encouragement that the proposal suggested by this study would not fall on deaf ears.

### **5.4.2. Existing Tax Incentives Relating to Persons with Disabilities**

In addition to tax relief, the government also provides certain tax incentives or special deductions under the Act to employers of persons with disabilities. These are detailed below.

#### *5.4.2.1. Existing Tax Incentives for Employers of Persons with Disabilities under the Act*

The Act provides a series of tax incentives to individuals and businesses that employ persons with disabilities. These incentives are meant to enhance the employment

opportunities of the disabled, as well as to compensate employers for any extra expenses arising from employing the disabled as opposed to employing those who are not. The incentives include:

#### *5.4.2.2. Equipment For Disabled Employees – Section 34(6)(e)*

Expenditure incurred by the employer for the provision of any equipment, or for the alteration or renovation of premises necessary to assist a disabled employee in the performance of his duties of employment, is deductible for tax purposes. These activities would normally constitute capital improvements, which generally would not qualify for a deduction for income tax purposes.

#### *5.4.2.3. Income Tax (Deductions for the Employment of Disabled Persons) Rules 1982*

An employer employing a physically or mentally disabled person qualifies for a double deduction in respect of remuneration of a kind allowable under section 33 of the Act. This includes any wages, salary, or allowances in respect of having or exercising employment.

#### *5.4.2.4. Income Tax (Deductions for Approved Training) Rules 1992*

A double deduction is also provided for any expenditure incurred in training any disabled person registered with the Department of Social Welfare who is not an employee of the company under:

- (a) a training program approved by the Minister of Finance, which is conducted in Malaysia; or
- (b) a training program conducted by a training institution.

However, the training program is for the purpose of enhancing employment prospects of the disabled person.

In addition, a special deduction is also accorded for the provision of facilities that benefit persons with disabilities.

#### *5.4.2.5. Provision of Facilities for the Disabled at Public Places- Section 44(9)*

A tax deduction is given to any individual who donates money or makes a contribution in kind (the value is to be determined by the relevant local authority) for the provision of facilities in public places for the benefit of disabled persons.

Although the above relief and incentives are commendable, it is obvious that recognition is given only to persons with disabilities. The only exception to this is the relief provided to parents where payment for a caregiver qualifies. The need to further recognise the contributions of caregivers is emphasised in the next section.

### **5.5. CAREGIVERS –THEIR NEED FOR SUPPORT**

The British Columbia Law Institute & Canadian Centre for Elder Law prepared a study paper entitled “Care/work: Law Reform to Support Family Caregivers to Balance Paid Work and Unpaid Caregiving” in 2009. The study explains how the laws in British Columbia enable caregivers to achieve a balance between their occupation and the discharging of their caregiving duties (for which they are not remunerated) and evaluates whether sufficient recognition is given to this free caregiving services in terms of value to society. It also suggests how the law should be amended so that it is more

receptive to the requirements of these voluntary caregivers and how public policies can be geared towards attaching greater value to the rendering of these caregiving services without payment.

Silverstein & Parrott (2001) emphasise that development of public policies and programmes should note the change in the demographical contours with the aged claiming a larger proportion and recognise that this translates into increased strains of caregiving. Therefore, they conclude that anticipatory measures should be instituted to facilitate the elderly to be able to care for themselves or through the aid of a caregiver failing which the whole burden will be transferred to the hands of the Government.

The British Columbia Law Institute (2009) study explains that the people under the supervision of “family caregivers” include aged parents, disabled children, those suffering from mental disorders, addicts, patients with or have survived serious diseases such as cancer and person recovering from surgery. In addition to caring for their own family, their services are extended to neighbours and acquaintances; they manage administering medicines, keeping appointments, helping with personal hygiene engage, giving support with passion, helping them to move around, and assisting with the work around the house such as cooking, purchasing and other chores either regularly or occasionally

The study explains that for this group of people, caregiving is not a choice because it involves the provision of care with affection and they don’t even think that it can be fulfilled by engaging just anyone. Further locating an appropriate candidate is difficult and cost constraint is another restrictive factor especially in small families where there are too few members to share the financial burden.

The study also acknowledges that the financial strain on the caregivers is mammoth and laments the inadequate attention to this matter by the Government has caused the standard of living of caregivers to recede further. It explains that undertaking the caregiving activities not only has additional disbursements closely associated with the provision of care but the caregiver's burden is enhanced further with curtailed hours available for them to be employed especially if the care required is extensive.

The study also recognises that the provision of caregiving services, through its adverse impact on the caregiver's employment, generates a reduction in income. A choice battle ensues, requiring a decision between whether to just continue with both their full-time job and the provision of caregiving services even though it has a detrimental effect on your health, or to give up the caregiving responsibility in the light of its incompatibility with holding a job or lastly to reject the job, bear with the ensuing poverty and continue with the caregiving activities.

In recognising that there is a need to distribute these caregiving costs to associated parties aside from the caregiver himself ranging from the person being cared for, their family, the employer of the caregiver and culminating with the community at large i.e. it has now become a public issue requiring the attention of policy makers. The study suggests "three different public policy approaches to compensation of, or income support for, caregivers: indirect compensation through tax policy; direct compensation through stipends and wages paid to the caregiver through various government programs; and pensions initiatives that recognize caregiving labour and the long term financial consequences of caregiving on pension security."

The current study concentrates on indirect compensation through tax policy, which will be discussed in the next section.

## **5.6. TAX RELIEF FOR CAREGIVERS OF PERSONS WITH DISABILITIES**

The use of fiscal incentives as a means of providing financial support is common government practice in various parts of the world. Strategies employed by the various governments in its attempt to eradicate child poverty included enhancing the rate of employment and raising financial support provided to low-income families (Smith et al., 2010). Smith et al. states that this was further augmented with the provision of Child Tax Credits and the Working Tax Credit, the former representing financial support to maintain children, and the latter serving as an incentive for parents to work to supplement their meagre income.

The British Columbia Law Institute (2009) acknowledges the substantial financial impact on the caregiver and lament that this has eroded the living standards of the caregiver attributing it mainly to the apathetic attitude of the Government in introducing remedial action. It explains that the financial burden commences with disbursements directly linked to the administration of care but this is further heightened by the fact that the caregiving activities reduces the hours available for gainful employment which varies with the degree of care necessary in each case. Although there has been a marked increase in caregiving activities and it has become quite a norm, Silverstein & Parrott (2001) state that Government funding to ease the financial burdens of caregivers is still lacking.

Although tax relief itself will not provide a major reprieve from the financial woes faced by a caregiving sibling, it would nevertheless provide some welcome respite. The study by the British Columbia Law Institute (2009) explains that tax relief indirectly compensates the caregiver by lowering his taxable income, thus also lowering his tax payable which favours his cash flow situation. In acknowledging caregiving as a valuable service to society and recognising the increasing costs associated with it, the tax policies should provide a relief because now the caregivers have less financial resources available for the settlement of their tax liabilities. This is in line with the objectives of tax policy which, aside from generating revenue for the state, should also encourage behaviours which produce economic advantages and benefit society as a whole, ensure an equitable distribution of income and provide subsidies to programmes with social value.

Tax benefits can be given through the provision of exemptions, allowance of a deduction or a crediting a credit and any of these can be pursued in providing a relief to caregivers as compensation for the additional costs borne by them or in sheer recognition of their sacrifices. However, the mode adopted must ensure that the benefit reaches the person for whom it is intended. Where the deductions or credit is restricted to the quantum of tax payable i.e. and excess is not refundable to the persons with disabilities or the caregiver, it loses its significance and becomes worthless

In Malaysia, however, we note that any tax relief given to caregivers of persons with disabilities is only given to the parents, the spouse or their children. No tax relief, credits or incentives are ever given to the brothers and sisters of persons with disabilities who, in many cases are required through the bonds of love, affection and family ties, to take care of a disabled sibling in the event of the death or incapacity of the parents or

because the disabled person himself remains unmarried due to his disability. Therefore, we now need to address our study objective of advocating for the provision of tax relief not just to the disabled person and parent and child caregivers but also to sibling caregivers. The position is well supported by existing literature.

Yanagisawaa et al. (2010), advocate that Government policy had a crucial effect on sibling caregiving. They observe that in many developing countries, communities recognised that their support was not sufficient and that government commitment is necessary. Additionally, Selwyn & Nandy (2011) are saddened by the fact that welfare policies continue to assume that 'families' comprise parents and children, and fail to consider the large number of children being brought up by relatives.

Similar sentiments are echoed by Seltzer et al. (1997), who feel that "all too often service providers have overlooked the needs of siblings for support and information about the disability" (p.403-404). It is obvious that sibling caregivers who face insurmountable obstacles each day are more likely to have significant financial and other support needs (Selwyn & Nandy, 2011). Therefore, to address these needs, Seltzer et al. (1997) suggest that government "should include siblings when they take a 'social inventory' of individuals who provide regular support to an adult with disabilities. They also recognise that "the concerns of many siblings are not only with the present situation but also with planning for the future when their parent may no longer be able to continue as the primary caregiver" (p.404).

We now look at the tax systems of our two neighbouring countries, Singapore and Thailand, and evaluate the tax relief offered to sibling caregivers of persons with disabilities.



## **5.7. TAX RELIEF FOR HANDICAPPED SIBLINGS IN SINGAPORE**

### **5.7.1. The Tax Relief**

Singapore's acknowledgement of the contributions made by siblings of persons with disabilities is evident from the enactment of section 39(2)(j) in the *Singapore Income Tax Act*. The Inland Revenue Authority of Singapore (2011) states on its website that 'handicapped brother/sister relief' is a relief to provide recognition for individuals supporting their handicapped siblings.

### **5.7.2. Eligibility to Claim**

Eligibility to claim the relief is extended to any person who has "supported [his] or [his] spouse's physically or mentally handicapped brothers/sisters who lived in Singapore in previous year" (Inland Revenue Authority of Singapore, 2011). The Authority also explains that a claim will be denied in the event that "someone [has] claimed any other reliefs on the same sibling" (Inland Revenue Authority of Singapore, 2011, at p.1). The following provides a lucid example:

*If your father claimed 'handicapped child relief' for your handicapped brother, you and your sibling cannot claim this relief on the same handicapped brother.*

### **5.7.3. Conditions Governing the Claim**

The disabled sibling should "have lived with [the claimant] in the same household in previous year [or] if not, [the claimant] must have incurred [Singapore] \$2,000 or more

in supporting [the disabled sibling] in previous year” (Inland Revenue Authority of Singapore, 2011).

Prior to 2010, an additional condition was that the disabled sibling should not have an annual income exceeding Singapore \$2,000 in the previous year, where income included all forms of taxable income (e.g., trade, employment and rental), tax exempt income (e.g., bank interest, dividends and pension) and foreign-sourced income (regardless of whether it had been remitted to Singapore). However, Singapore’s Minister of Finance stated in the 2010 Budget speech that “for handicapped-dependant-related reliefs, the income threshold condition will be removed in recognition of the extra resources and attention needed in providing care to the disabled. Hence taxpayers will be able to claim the reliefs regardless of the income of the handicapped dependant” (Shanmugaratnam, 2010).

#### **5.7.4. The Quantum Claimable**

The caregiving brother or sister is able to claim Singapore \$3,500 for each handicapped brother/sister. However, if the same handicapped sibling is supported by more than one person the relief of Singapore \$3,500 is shared by all the relevant caregivers.

## **5.8. TAX RELIEF FOR HANDICAPPED SIBLINGS IN THAILAND**

### **5.8.1. The Thailand Revenue Code Amendment**

Section 47, of the Revenue Code of Thailand “sets out the tax deductible items . . . for personal income tax calculation purposes” (Suvarnapunya et al., 2009). This section basically provides for personal tax relief.

In 2009, the *Thailand Revenue Code Amendment Act No. 37, B.E. 2552* (2009) added an additional item to the list of items under Section 47 which would “allow taxpayer who actually support qualifying disabled persons to take an allowance” (Suvarnapunya et al., 2009).

### **5.8.2. Eligibility to Claim**

Eligibility to claim relief is extended to any person who is taking “care of a disabled or incapacitated family member or care of a disabled or an incapacitated person other than a family member” (PwC, 2011).

### **5.8.3. The Quantum Claimable**

The claimable amount is Thai Bhat 60,000 in respect of each “disabled person when calculating his/her net taxable personal income” (Suvarnapunya et al., 2009).

## **5.9. THE GAP**

Malaysia has numerous forms of tax relief for persons with disabilities and also some tax relief for caregivers. However, these are only for the disabled person, the spouse, and children: no relief is available for sibling caregivers of persons with disabilities. As previously demonstrated by the examples of Singapore and Thailand, such relief is not novel.

## **5.10. CONCLUSION**

The above discussion confirms the need for government and policy makers to give due recognition to the caregiving services provided by siblings. While the Malaysian government does not have a lackadaisical attitude towards recognizing the contributions of caregivers, as evidenced by the provision of tax relief to caregivers who are parents, spouses or children of persons with disabilities, our endeavour here is to convince the government of the need to extend that relief to sibling caregivers as well.

However, this study is not founded on a simple request to government for such a tax relief. As evident from the earlier chapters, and supported with convincing literature, a solid attempt has been made to rationalise the whole concept of accountability (especially in relation to persons with disabilities), consolidate it with the principles of Vedic philosophy (in essence, Hinduism), and view the result through the lens of Schumacher to offer critical evidence to justify the introduction of tax relief for sibling caregivers. The exercise illustrates the suffering and pain endured by sibling caregivers, the sacrifices they have made and the financial woes they put up within undertaking a responsibility which should, rightfully, be that of government.

This chapter provided examples of various measures that can be taken and, specifically, tax relief that can be given by the state in the discharge of its accountability to society, in line with the final research question identified earlier. Further, the chapter has informed that the concept of tax relief for sibling caregivers is not something new, innovative or unique as such relief already exists in Singapore and Thailand.

Therefore, although the concluding objective here is to advocate for the introduction of tax relief for sibling caregivers in Malaysia, this study encompasses a wider agenda involving a conceptualisation of accountability which draws from Vedic philosophy and uses the theoretical lens of Schumacher to justify not just the above objective, but the harmonisation of tax policies in this region.

The next chapter discusses the methodology used to achieve the research objectives and resolve the research questions.

## **CHAPTER 6**

### **METHODOLOGY**

#### **6.1. INTRODUCTION**

The previous chapters provided the foundation of the research process in the form of an extensive review of literature in the areas of accountability to society, accountability and theology, and the essential principles of the Vedas in relation to accounting and taxation. This culminated in a treatise on the philosophy of Schumacher.

This study revolves around the question of how a conceptualisation of accountability, drawing from Vedic philosophy and using an appropriate theoretical model, can be used to explain what motivates siblings to become caregivers, and what role the state plays in inculcating the accountability concept in society. This chapter considers the most appropriate methodological approach to achieving the objectives of the study.

Research is an activity undertaken to learn more about our environment and the impact we have upon it (Susela et al., 2004), and the approach adopted in conducting that study is referred to as the methodology (Silverman, 2000). One of the greatest attractions for accounting researchers is that accounting research cuts across many boundaries, divides researchers into political and philosophical camps, and brings world views into sharp conflict. (Ryan, Scapens & Theobald, 2002, as quoted by Susela et al., 2004). Initially, the development of accounting was influenced by changes in the social and business environments. It was not “driven by research and theory development per se”, but during the fifties there was a call for the use of theorising and science in accounting as a way to imbue accounting with greater rationality and theoretical underpinning. (Susela et al., 2004).

This chapter introduces the theoretical perspectives in accounting research in section 6.2., followed in 6.3. by a justification of the research paradigm being used. This leads us to the study methodology employed (i.e., autoethnography) in section 6.4., and a conclusion in section 6.5.

## **6.2. THEORETICAL PERSPECTIVES IN ACCOUNTING RESEARCH**

The theoretical perspectives in accounting research have evolved tremendously over the last two centuries. The different approaches that have arisen in the field of accounting research are the positivist (mainstream), the interpretative and the critical approaches.

### **6.2.1. Positivist Approach**

Positivism has been dominating accounting research for last two centuries. In criticising its dominance, Gaffikin, (2006) scoffs at the notion that research on society in general and the human element in society can be conducted using scientific methodology

From the ontological position, positivists advocate “an objective reality that is causally determined and knowable to observers” (Susela et al., 2004). From the epistemological position, however, they approach a study inductively i.e., by viewing separately “theory and observation” with the latter’s role being to test the former with the ultimate goal of confirming or verifying it.

Chua (1986) explains further that current accounting research is governed by a set of assumptions founded on a deductive paradigm which, although is not without its

advantages but has placed a restrictive handcuff on the areas of research and the use of different methods of research thus hindering the progress of accounting research

Susela et.al (2004) explains that positivism is characterised by a search for universal laws from which hypotheses may be deduced. This is followed by a discussion of data and ends with an assessment of whether the data supports the hypotheses through the employment of rigorous samples, surveys and statistical methods. This is evident in the cases of behavioural or multi-probability studies of investor reactions to financial information, the efficient market hypothesis and agency theory.

Therefore, when undertaking a philosophical appreciation of accounting and accountability as in this study, the irrelevance of a positivist approach is evident as it involves a comprehension of the trials and tribulations of the sibling caregivers which cannot be measured in statistical terms.

Another approach is the interpretive methodology which is discussed in the next section.

### **6.2.2. Interpretative Approach**

The fundamental belief of those researching from an interpretative perspective is that people are purposeful and basically orderly. Actions are endowed with subjective meaning; through communication, the intent of a person's action can be subjectively discovered or, more likely, made sense of. Continuous social interaction allows us to interpret activities and give them meaning, and even allow for the construction of shared norms (Susela et al., 2004).



Again, the relevance of this approach is questionable here, as this study does not involve an interpretation of a practice or culture but instead is an attempt at conceptualising to explain what motivates siblings to become caregivers and how the state inculcates accountability in society

That leads us to the third approach, the critical perspective methodology

### **6.2.3. Critical Perspective Approach**

Essentially, critical theory commenced with the work of social theorists and philosophers from the Frankfurt School in Germany. It was passed on to Habermas (one of their students) and then handed down as legacy until today (Gaffikin, 2006).

The theory rejects positivism because of its “lack of self-reflection which . . . reduce(s) epistemology to a crudely mechanical methodology” says Gaffikin, (2006). The generation of knowledge necessitates the recognition of human agency, i.e., that one must know the source of the knowledge or else he will just be assimilating what is being propagated by the dominant and powerful members of the society (Gaffikin, 2006).

Several accounting studies have advocated the use of the critical perspective. A pioneer was Richard Laughlin who recognised the failure of the positivists to comprehend the system of accounting and in consequence its applicability to practice. His work involved resolving real life controversial accounting subjects, situations and scenarios by employing the critical theory. He was followed by Jane Broadbent, Jesse Dillard and

others further advocating the use of a critical orientation to seek answers for problems in accounting.

Laughlin (1999) enumerates the features of accounting from a critical perspective and highlighting that firstly, a contextual approach is adopted, secondly, recognition is given to the fact there are social, political and economic consequences in the practice of accounting, thirdly, it encompasses all views; i.e. individuals, organisations and society at large and lastly it permits the engagement of accounting with other disciplines, thus expanding its horizons and perceptions. This justifies the introduction of the critical element in accounting research.

Critical accounting has influenced research in many countries. In 2002 a special issue of the journal *Critical Perspectives in Accounting* was devoted to “Critical Accounting in Different National Contexts.” In this issue Broadbent asks why we need critical accounting. Her response argues that in a world pondering over the allocation of scarce resources “We need to ensure the use of accounting does not represent certain interests at the expense of others” (p.444). She continues, “Constructions and interpretations of accounting information must pay attention to the cultural imperatives of those it seeks to control as well as those who are using it as a tool of control” (p. 444). Thus, critical accounting seeks to unmask the often hidden interests of those who would seek an unjust allocation of a society’s scarce resources so that all interests in society can benefit. The spectacular corporate collapses and frauds seen early in this century – and before – clearly indicate that such maladjusted interests exist.

The critical approach does not provide an alternative method of research but is an alternative method of evaluating and validating research. By emphasizing social, contextual and humanitarian issues and deemphasising the scientific, it has laid the groundwork for the move to the postmodern and pluralistic views of the growth of knowledge

From this examination of the three approaches, it becomes obvious that the approach to be taken in this study is the interpretative perspective because this study is seeking to understand accountability motivation for sibling caregivers justified through a conceptualising of accountability and explained using the lens of Schumacher.

Having settled on the use of the theoretical perspective for the study, we now turn to the paradigm of research methodology to be adopted.

### **6.3. QUALITATIVE RESEARCH APPROACH**

The approach to research generally founded on two distinct paradigms i.e. the quantitative or qualitative approach. Creswell (2005) explains that in quantitative research having decided on what he intends to study, the researcher commences with precise and definitive questions, meanders through assimilation of numerical data which is subject to a statistical analysis and objectively reports in an unprejudiced and impartial manner. Whereas in the case of qualitative research, relying on the views of persons interviewed, the researcher starts by asking wide and generalised questions, collecting data along the way which are textual in nature and highly descriptive and

which are analysed to reveal emerging themes which permits a subjectively conducted inquiry.

A quantitative approach will not have been appropriate in this study because this approach employs deductive logic utilising existing theoretical and substantive prior knowledge to conceptualise specific situations, and to predict what will happen to particular people or groups, whereas in this study we have to be inductive i.e. attempt to describe the lives of siblings caregivers of persons with disabilities and understand their sacrifices, contributions and burdens. Also, in researching such feelings, emotions and experiences the findings are perpetually evolving with data collection and data analysis being conducted simultaneously which necessitates an inductive approach absent in quantitative methodology.

As this study entails a conceptualisation of accountability linked to Vedic principles precipitated through the lens of Schumacher's philosophy and with particular reference to awarding tax relief to siblings of disabled persons, obviously the qualitative approach is most suited.

Different strategic methodologies for research have been formulated in the qualitative paradigm, each being named differently (Ellis & Bochner, 2000). As this study was inspired by the researcher's own experience in this dilemma, the most suited approach seems to be autoethnography.

#### **6.4. AUTOETHNOGRAPHY**

As stated earlier, the motivation for this study stemmed from my personal experience where I could not justify why the costs incurred in providing medical aid for my disabled sister did not qualify for a tax deduction or relief for me or any one of my siblings. My initial reaction to this was similar to that of Sylvia (in Ellis, 1999) who says “I thought I had to keep my personal experience out of my research . . . if I want my study to be valid . . .” I found great solace in the words of Carolyn Ellis, Sylvia’s supervisor, when she states categorically in describing autoethnography: “well, I start with my personal life. I pay attention to my physical feelings, thoughts, and emotions. I use what I call systematic sociological introspection and emotional recall to try to understand an experience I’ve lived through. Then I write my experience as a story” (Ellis, 1999).

My confidence was further uplifted with the views of Anderson (2006) that the undertaking of an autoethnographic quest is unique in that it is motivated by the urge to understand one’s self, bridging biography with society, knowledge of the self through a comprehension of our lives, our characteristics and emotions which is related to and forms a part of, the society and culture in which we company-exist.

Also, Miles (2002) remarks that “the people who take an interest in disability are likely to be either disabled people themselves and their families, or people already having a standard of living (both economic and psychological) sufficient for them to have some margin of confidence permitting them to look around and be moved by the needs of others.”

This convinced me of the appropriateness and suitability of using an autoethnographic methodology for my study.

#### **6.4.1. What is Autoethnography?**

Autoethnography offers a particular way to situate oneself within the research process and its written product by making oneself the object of research and by developing a “reflexive connection between the researcher’s and participants’ lives” (Ellis 2004, p.30). Reed-Danahay (1997, p.145), as cited by Doloriert & Sambrook (2011), defines autoethnography as “research (graphy) that connects the personal (auto) to the cultural (ethnos), placing the self within a social context.” This is further confirmed by Ellis et al. (2011) who state that essentially the method of autoethnography narrates an autobiography ethnographically because it involves writing about the person’s past experiences although at the time of occurrence no intention of publishing details of the events was conceived. Therefore, usually “these experiences are assembled using hindsight”, assisted by interviewing related persons and consulting other supporting evidence in the form of recorded journals and photos which facilitate the recalling of events.

The use of autoethnographic methodology is not something new. As Learmonth & Humphreys (2012) indicate, it is “an emergent practice concerned with writing about one’s own self and identity in the context of organizational studies.” They quote the following recent examples: “[Ford & Harding, 2008; Ford et al., 2010; Grey & Sinclair, 2006; Humphreys & Learmonth, 2010; Karra & Phillips, 2008; Keenoy & Seijo, 2010; Watson, 1995, 2008].”

Both the interpretivist and realist schools concur “on . . . the complete member status of the researcher/self or “I” within this research” (Doloriert & Sambrook, 2011). Learmonth & Humphreys (2012) fittingly endorse this view with a quote from Coffey (2002) that “the self and the field become one.” This is further confirmed by Spry (2001) when he describes an autoethnography as “ . . . a self-narrative that critiques the situatedness of self and others in social context.” Butler (2009) explains that “autoethnography is a qualitative research methodology that emphasizes a more personal, almost intimate level of study. It renders the researcher-participant opportunities to explore past and present experiences while gaining self-awareness of his or her interactions and their socio-cultural effects.”

The characteristics of autoethnography are expounded by Learmonth & Humphreys (2012) when they cite Anderson (2006, p. 377) who notes that self-declared autoethnographers typically publish “especially (although not exclusively) on topics related to emotionally wrenching experiences, such as illness, death, victimization, and divorce” . . . [but] . . . also [on] . . . “the mundane.” Further, they illustrate that “the autoethnographic label is often also deployed in many other contexts and forms that Richardson and St Pierre (2005, p. 962) call ‘creative analytical practices’ for example, in forms of performance ethnography, fiction stories and other less conventional approaches”. To summarise effectively, they borrow the comments of Charmaz (2006, p. 397): “ . . . [w]hat stands as autoethnography remains unclear and contested. This term lumps [together] interesting, boring and revealing memoirs, recollections, personal journals, stories and ethnographic accounts under the same name.”

Aptly, Anderson (2006) describes “this scholarship has been linked, explicitly and implicitly by different authors, to various “turns” in the social sciences and humanities:

the turn toward blurred genres of writing, a heightened self-reflexivity in ethnographic research, an increased focus on emotion in the social sciences, and the postmodern scepticism regarding generalization of knowledge claims.”

Therefore, autoethnography is an appropriate methodology to adopt in this study as one of the sparks that ignited the motivation to undertake it was my frustration towards the lackadaisical attitude of the government in giving tax relief to siblings of disabled persons. The interaction with similar members of “the family” (i.e., siblings of persons with disabilities) will help illuminate whether or not this frustration is justified. However, although we are all in families with similar responsibilities, fears, traumas etc., nevertheless it is not uncommon for members in a group to display variations in their commitments, values and beliefs and therefore, in some cases, being a member only confers a limited advantage for studying the characteristics of that ‘family’ (Anderson, 2006). Hayano (1979, p.102) adds credence to the above when he states members in a group may hold differing views, which are not only contradicting but also changing from time to time.

In a nutshell, autoethnography enables and unites the researcher and the researched phenomena, the area being researched and the field or setting. There is an undeniable reflective relationship between the seeker and what is being sought. Therefore, this unison adds authenticity, genuineness and provides a faithful representation of the actual situation or dilemma



#### **6.4.2. The Move to Autoethnography**

The move to autoethnography came in the wake of the realisation that traditional methods were stifling the conduct of social studies in an expanded form. This is obvious with Ellis (1997) expressing that conducting an analysis based on traditional sociological methods to frame an evocative study using autoethnography will violate its very significance and reliability and Denzin (1997, p.228) writing that an autoethnographic endeavour which is evocative can invoke emotions epistemologically, enabling the reader to sense what the others in the group. Ellis & Bochner (2000, p.744) promote evocative autoethnographic studies as the avenue for narration of a story similar to biographical venture or novel which serves to demolish the barriers between literature and social science.

The move of social science research away from the traditional scientific school emerged when the limitations of social science in terms of ontology, epistemology, and axiology raised an anxiety for many scholars (Ellis & Bochner, 2000). Ellis et al. (2011) confide that this is based on the following revelations arising from various studies: the representation of findings of truths and facts by scientists were inseparable from the “vocabularies and paradigms” used by them (Kuhn, 1996; Rorty, 1982); the rejection of and the non-desirability of a standard narration to be used universally (De Certeau, 1984; Lyotard, 1984); the emerging recognition of a fresh association between textual contexts, writers and the spectators (Barthes, 1977; Derrida, 1978; Radway, 1984); and finally the acceptance of the fact that narration presented a different way to think and feel and assist others to understand themselves because they were phenomenal, saturated with complexity and constitutive to facilitate moral and ethical teachings (Adams, 2008; Bochner, 2001, 2002; Fisher, 1984).

As Ellis (2009, p.84) asks, “Why does social science have to be written in a way that makes detailed lived experience secondary to abstraction and statistical data?” A sense of realisation began to descend on the minds of scholars from various fields; over time, they started to recognise the many advantages that could be gained if the study of social sciences could be “closer to literature than to physics, if they proffered stories rather than theories, and if they were self-consciously value-centred rather than pretending to be value-free” (Bochner, 1994).. This played a crucial role in the advent of autoethnography.

Anderson (2006) shows emphatically how autoethnography has successfully emerged as a methodology of research. He states that although it initially “remain[ed] largely marginalized in mainstream social science venues, due to . . . [its] . . . rejection of traditional social science values and styles of writing, [it has] gained entrée into many traditionally realist qualitative-research journals (e.g., *Journal of Contemporary Ethnography*, *Symbolic Interaction*, and *Qualitative Sociology*) and . . . [has] . . . been influential in the creation of newer postmodern-friendly journals (e.g., *Qualitative Inquiry*), handbooks (e.g., Denzin & Lincoln’s *Handbook of Qualitative Inquiry*), and even book series (e.g., the AltaMira Press series on “Ethnographic Alternatives”).”

However, this methodology is comparatively difficult, because on one hand we are a member of ‘the family’ i.e., siblings of persons with disability but we must also not lose sight of our role as a researcher. Strathern (1987) highlights the difference between “the ethnographic researcher” and the other members of the family being studied. She emphasises that the dual roles of being “a member and a participant in the social science community” as well as a “social scientist”, require the researcher to be engaged in the

activity of simultaneously performing the dual role of engaging in the activity whilst preparing the relevant documents and analysing them. (Anderson, 2006). This places a greater strain on the autoethnographer because, whilst other researchers just need to participate in the setting, the autoethnographer has in addition to this, the task of documenting all happenings and conversations that transpire there, thus making his work a hectic and arduous multi-tasked engagement (Adler & Adler 1987, as cited by Anderson, 2006). In addition, the autoethnographer needs to not only speak and interact with the participants but also make notes and tape their responses resulting in the research work bordering on schizophrenia (Adler & Adler 1987, as cited by Anderson, 2006).

Advocates of this methodology argue that it may be better for the researcher to extend their period of engagement with the fieldwork so as to allow them more time to complete all their tasks. However, expanding the time frame for observation may enhance the documentation task further plus it may distract the researcher from that which he had originally intended to study (Anderson, 2006). Researchers slowly came to recognise that the sovereignty of the positivist and scientific approach in the quantitative paradigm was flawed and harboured serious problems, especially in a social science environment entailing a study of feelings, emotions and sentiments. Epistemologically, there is no theoretical platform to explain how we know certain things and, ontologically, the nature of the existence of such non-quantifiable factors required the emergence of a new approach, paving the way for the birth of autoethnography.

### 6.4.3. Criticism of Autoethnography

Ellis et al. (2011) have efficiently compiled the criticisms thrown at autoethnography. They start with the dismissal of autoethnography on the grounds of “social scientific standards as being insufficiently rigorous, theoretical, and analytical, and too aesthetic, emotional, and therapeutic (citing Ellis, 2009; Hooks, 1994; Keller, 1995), through “doing too little fieldwork, for observing too few cultural members, for not spending enough time with (different) others (citing Buzard, 2003; Fine, 2003; Delamont, 2009). They also note the claim that autoethnographic researchers are “using personal experience”, and that they “not only use supposedly biased data (Anderson, 2006; Atkinson, 1997; Gans, 1999), but . . . [are] also navel-gazers (Madison, 2006), self-absorbed narcissists who don't fulfil scholarly obligations of hypothesizing, analyzing, and theorizing.”

The brickbats continue when even in terms of writing an autobiography, where autoethnography is regarded as unsuitable because of its lack of art when seen from an “aesthetic and literary” viewpoint (Ellis et al., 2011). Further the autoethnographers themselves are criticised as trying to portray themselves as scientists by “catering to the sociological, scientific imagination” (Ellis et al., 2011). Others frown on their neglect of the literary, artistic imagination and the need to be talented artists (Gingrich-Philbrook, 2005, as cited by Ellis et al., 2011). Also, Moro (2006), as cited by Ellis et al., 2011) believes it takes “a ‘darn good’ writer to write autoethnography” (Ellis et al., 2011). opine that to attempt an autoethnographic endeavour, one must be excellent at writing.

#### **6.4.4. Response to Criticism of Autoethnography**

Ellis et. al. (2011) embark on a rebuttal to these criticisms by pointing out that they “wrongly view science and art as opposite poles and this is rectified by autoethnography which serves to dispel the dualism in the two. Autoethnographers acknowledge the need for rigour, theory and analysis in a research but they also recognise the need to include elements of emotion, therapeutics and phenomena both from a social and personal angle which necessitates the writing and research in general to be evocative and aesthetic. (e.g., Ellis, 1995, 2004; Pelias, 2000, as cited by Ellis et al., 2011). Indeed, they identify the issue for autoethnographers when they state succinctly that the main issues for autoethnographer is to identify his reader, evaluate how his work will affect the reader and whether it can evoke a continuous flow of conversation (Ellis et al., 2011).

Ellis et al. (2011) argue that the parameters used to evaluate other research methods may not be an appropriate basis for gauging the worth of autoethnography. They eloquently retort that without determining the ultimate goal it would be futile to evaluate the avenues for achieving it. Obviously autoethnographers hold a varying opinion on what constitutes a study on social science and they quote Rorty (1982) who feels these differing viewpoints is not a matter requiring a resolution but rather it is a variation to be accepted. They accordingly submit that autoethnographer opine that the research and ultimate write-up should be to bring about justice in society having no obsession with accuracy but just a text which is both analytical and accessible to make the world a better place to live in. (citing Holman Jones, 2005).

Having been a caregiver for a disabled sibling enables me to aptly describe the pains, anguish, trials and obstacles faced by this category of society. Therefore, in undertaking this study to advocate the introduction of tax relief for sibling caregivers of persons with disabilities, what better methodology to adopt than autoethnography? It allows the opportunity to place myself within the research process, and actually tell my own story, saturated with tones of reliability and validity. And, since it is my own experience, how can I get it wrong?

Just as in any comparative composition, where generally the strengths of one component obviously become the weakness of a competing value, similarly the naysayers of autoethnography are merely harping on the supremacy of quantitative research (in essence a scientific approach) on the grounds of rigour, theory and analysis. However, they forget that in dealing with human factors, attempting to understand the inspiration to become a sibling caregiver, in researching the psychological impact of caregiving, in studying the financial burden borne by these people, the use of statistical methods just becomes irrelevant. Therefore, instead of relying on the words of other participants that I cannot vouch for, would not my own words, experience and encounters present a clearer picture of the actual phenomena?

## **6.5. EVOCATIVE VERSUS ANALYTICAL AUTOETHNOGRAPHY**

However, Anderson (2006) was not satisfied with just having evocative autoethnography in the absence of an analytical outlook. He argues that we should “not [be] content with accomplishing the representational task of capturing what is going on in an individual life or social environment” but instead show a “commitment to an analytic agenda.” The study, he feels, “is not simply to document personal experience”

but to provide an “insider’s perspective or to evoke emotional resonance with the reader.” He endeavours to remind that “the defining characteristic of analytic social science is to use empirical data to gain insight into some broader set of social phenomena than those provided by the data themselves.” Anderson (2006) further refers to “Robert Murphy’s analytic autoethnography ‘The Body Silent’” and explains that “Murphy . . . uses his experience . . . as a way of understanding the social world of people with disabilities and analysing how their experiences also reveal much about broader social structures and processes.” This enables him “to address numerous areas of theoretical interest.”

The differentiation between evocative autoethnography and analytical autoethnography is vividly portrayed by Ellis & Bochner (2006) where they describe the former “as a journey; [and the latter] as a destination.” The former features “caring and empathizing” whilst the latter involves “abstracting and controlling.” Effectively, evocative autoethnographers “want to dwell in the flux of lived experience” whereas the analytical autoethnographers “want to appropriate lived experience for the purpose of abstracting something they call knowledge or theory.”

Similarly, though this study started with the researcher’s personal experience, it was expanded through interviews of and conversations with, other siblings of persons with disabilities. This provided for generalization, with the aim of creating a strong platform to advocate the introduction of some form of financial aid for such people. However, the objective of the study is not just to describe the pain and anguish of siblings of persons with disabilities, but rather to understand the troubles and pressures plaguing these people so as to raise awareness of the need for a suitable tax relief for such people, equipped with first-hand knowledge of their tribulations. By understanding my own

experience, and the experience obtained through the interviews and contacts with other siblings in a similar predicament, this study will achieve “the definitive feature of analytic autoethnography [which] is this value-added quality of not only truthfully rendering the social world under investigation but also transcending that world through broader generalization” (Anderson, 2006).

As is the case with any methodology, there is always an advocating camp and a dissenting one. We have seen the bouquets showered on the practice of autoethnography but as Learmonth & Humphreys (2012) declare: “in the broader social sciences . . . [autoethnography is] a genre of work which has made significant strides as a research strategy in recent years, but not without its conceptual controversies and practical difficulties.” Therefore, we turn now to view the advantages and disadvantages of autoethnography as a methodology.

## **6.6. ADVANTAGES OF AUTOETHNOGRAPHY**

Reed-Danahay (1997) illustrates the boons of autoethnography when he states “of course, there are rewards, too: For example, you come to understand yourself in deeper ways. And with understanding yourself comes understanding others. Autoethnography provides an avenue for doing something meaningful for yourself and the world.”

Anderson (2006) clearly enumerates the various benefits of adopting this methodology in the present study. He commences with “one obvious advantage . . . is that the autoethnographer has multiple reasons to participate in the social world under study, and thus, multiple incentives to spend time in the field.” This is evident from the fact that the “autoethnographic researchers have been able to meld research goals with a



variety of interests”, including making a living (e.g., Ouellet 1994), achieving personal leisure identities (e.g., Mitchell, 1983), and pursuing personal spiritual goals (e.g., Marti 2005). He continues, stating that “ethnographers who are able to meet other needs or interests while engaging in research have a unique opportunity to use life’s precious time efficiently.”

The “second advantage of autoethnography involves the access that it provides to ‘insider meanings’ because the researcher is also a member of ‘the family’” (Anderson, 2006). He emphasises that this “methodological advantage of being personally identified and involved in the social world under study is that it gives the researcher an added vantage point for accessing certain kinds of data.”

Anderson (2006) continues rarely does a researcher engage in a scholastic endeavour closely related to their own lives but this is the very essence of autoethnography which facilitates an engagement with our personal experiences explored in the context of a scholarly research. The resultant advantage is a broader social understanding enriching an understanding of ourselves

Chang (2007) also identifies three areas in which the benefits of autoethnography clearly lie. First, he argues that it is both reader and researcher-friendly. For the researcher, being the source themselves, they face no obstacles in accessing the data. In addition, they are advantaged by the fact that the complete and all-inclusive data is perpetually with them thus facilitating the whole research process from collection, through analysing and interpreting, to arrive at conclusions.

For the readers he contends that a style of writing with a personal touch to engage the reader is far more appealing than the traditional academic styles. His contention is supported by the view of Nash (2004) that “scholarly personal narratives liberate researchers from abstract, impersonal writings and touch readers’ lives by informing their experiences.” He notes that Gergen & Gergen (2002) eloquently remark that when the researcher becomes the ‘researched’ he is released from the bonds of conventional writing styles and is able to use words which appropriately describe his feelings, employing colloquial language and words which express and echo the true emotions.

Chang’s second contention is that autoethnography “enhances cultural understanding of self and others.” He believes that “autoethnography is a useful tool for comprehending oneself and the ‘family’”. He goes on to point out that two fundamental characteristics of comprehending oneself is “self-reflection and self-examination” (Florio-Ruane 2001; Nieto 2003, as cited by Chang, 2006), and that these features are evoked not only by engaging in an autoethnographic writing but also crystallises from the reading the stories of others (Florio-Ruane 2001; Nash 2002, as cited by Chang, 2006).

His final support is that autoethnography is that it builds a cross-cultural environment with each participant endeavouring to fit in. He makes reference to Coia & Taylor (2006), and experiments with “co/autoethnography” involving their education students in which “the authors witnessed that students’ self-awareness and cultural understanding were broadened and their teaching philosophies and practices became more inclusive and sensitive to others’ needs.” Chang (2006) notes the many facets of ‘self-transformation’ where each member reaches out to other members in the ‘family’ with an urge to learn about a different culture and this evokes an appreciation of the other’s lives thus diminishing differences and propagating a sense of acceptance crystallising in

an harmonious communalism. He concludes that this enhanced self-awareness coupled with a good understanding of the others serves to rectify cultural misapprehensions, cultivates cross-cultural acceptance and culminates in a healthy solidarity. However, autoethnography is not devoid of disadvantages, which are described in the next section.

## **6.7. DISADVANTAGES OF AUTOETHNOGRAPHY**

Anderson (2006) proclaims that “all methodological approaches have their limitations.” However, “competent researchers must acquire not only the ability to use various research skills but also the acumen to judge when some kinds of research are likely to prove more productive than others.” In acknowledging these limitations, I have indicated how these have been addressed in this study.

A good start would be to read the words of Ellis (1999, pp. 671-672) who exclaims, “Oh, it’s amazingly difficult.” She reiterates that most people especially “social scientists don’t write well enough to carry it off.” They lack a contemplative and reflective disposition to fully understand “their feelings or motives or the contradictions they experience”, and lack the patience to be “observant enough of the world around them.” They are thus are unsuited for the demands of autoethnography with its self-questioning nature. She illustrates that embarking on the journey of autoethnography involves “confronting things about yourself that are less than flattering”, and facing “a lot of fears and self-doubts . . . and emotional pain.” She contends that the actual study only commences when this pain is unbearable and, most importantly, remarks that autoethnography includes “the vulnerability of revealing yourself, not being able to take back what you’ve written or having any control over how readers interpret it.” Your

work and the events in your life are laid out openly, inviting critique, and she warns that “it can be humiliating.”

Anderson (2006) nevertheless remarks that the participation on the field should be cautiously monitored to ensure that the active involvement does not overshadow the research goal nor is the observation and recording of information subjugated in any manner. The researcher in this study has been engaged in the tax field for almost three decades and so has no interest in diverging from his interest.

Anderson also expresses reservations on the advantage of being a member of “the family” in that because of the “variable nature of member values and beliefs, autoethnographers must assiduously pursue other insiders’ interpretations, attitudes, and feelings as well as their own.” This was clearly seen throughout the conduct of the interviews and contact conversations in the present study, which has been adequately structured to address all these concerns. The concerns have been clearly identified in the findings to lend greater credibility and reliability to the study.

Delamont (2007) also details her “objections to auto-ethnography.” First, she claims “auto-ethnography cannot fight familiarity...in our own society anyway even when we have data.” Her second reservation is that “the other actors will be . . . identifiable and identified”, in spite of whatever disclaimers or statements about fictions are included. The third objection is similar to that of Anderson (2006) in that “research is supposed to be analytic not merely experiential.” Her fourth is that “autoethnography focuses on the powerful and not the powerless to whom we should be directing our sociological gaze.” Next is that “sociology is an empirical discipline and we are supposed to study the

social” and not be “obsessing about ourselves.” She concludes with a final objection that “we are not interesting enough to be the subject matter of sociology.”

In terms of familiarity, this study is not merely to illustrate the feelings and emotions of siblings of persons with disabilities, but rather its implications or suggestions going forward are to justify the introduction of tax relief for sibling caregivers. The only detailed revelation of fact is in the researcher’s own experience; in this case the person with a disability is deceased so any form of recognition has no significance. As for Delamont’s third objection, this study is not merely evocative but analytical enough to bring about a change in government policy. The interpretative perspective of this study endeavours to provide a deeper understanding and lays the foundation to suggest the role for the state in making available a benefit for the powerless, the siblings of persons with disabilities in this case and this clearly defeats the fourth objection. The last two objections are irrelevant here because the personal experience of the researcher only serves to get the ball rolling; in essence, the study is an analysis of a social problem. To further ensure the viability of this study we have noted Chang’s (2007) “Pitfalls to Avoid in Doing Autoethnography”; great care has been taken to circumvent their impact on this study.

## **6.8. PITFALLS TO AVOID IN DOING AUTOETHNOGRAPHY**

Chang (2007) earnestly cautions that although the use of autoethnography gains momentum it has not been spared of criticism He is quick to add, however, that this does not mean that this method has inherent faults but instead it serves to remind the researcher to be careful, circumvent situations that would attract flak and steer clear of prospective areas of criticism. The five pitfalls that he has identified are detailed below

with a corresponding deliberation of the precautionary actions taken in this study to preclude them.

#### **6.8.1. Attention on the Researcher versus the “Family”**

Chang (2007) reminds us that culture is intrinsically a characteristic representation relating to a group of people where an interdependent relationship subsists. Therefore, he says an autoethnographic study should be reflective of this reciprocal affiliation. He cautions the researcher against a unconscious concentration on himself as he unravels his own stories without recognising the contextual relationship that it bears with the stories of the other members in the group. This form of introspective self-indulgence would not be an autoethnographic study but rather an all revealing biographical account of oneself. Recognising this trap, this study only starts with the personal experience of the researcher; the bulk of the study focuses on the stories of respondents that were interviewed.

#### **6.8.2. Lack of Focus on Interpretation as opposed to Narration**

Chang (2007) fears that many researchers are so immersed in the process of relating their story that they forget the goals of an autoethnographic study are to interpret the culture being studied and to analyse the text of the various stories that unfold. He cautions against the lure to be enticed with the narration of the stories at the expense of conducting a detailed analysis and providing an effective interpretation. Although the interviews conducted in this study were based on unstructured questions that allowed respondents to speak freely, they were conducted in a manner that did not allow the

respondents to stray away from the focal point of the impact on the siblings of caring for a person with a disability. Further, the use of the NVivo application facilitated the analysis of interview contents to provide a basis for reliability, validity and verification.

### **6.8.3. Recollection Based on Personal Memory as the Main Source of Data**

Chang's third reservation relates to excessive reliance on one's own memory as a data source. He cautions that one must not overlook the fact that one's own memory, although an excellent and exclusive reservoir of information, is not accessible to other researchers and readers. He cites the reminder of Muncey (2005) that the stories from memory are usually moulded and designed selectively and recited in the context of their personal experiences and although does not constitute an untruth but nevertheless the information provided is censored. His worries revolve around the issue of validity because the evidence adduced originates from a sole source i.e. the researcher himself, without any avenue for cross-checking or verification and therefore, the question of a lack of objectivity arises. Acknowledging that although this issue of undue subjectivity is not of paramount importance in a qualitative study but nevertheless he recognises that a multi-sourced information base renders the research to be more readily acceptable.

As a defence against this and to add authenticity to the autoethnographic study conducted, he suggests that this internally produced data should be augmented with external verifiable information to illustrate that the narration of the events were accurate and valid and this can be achieved through the use of documents and the conduct of interviews with relevant parties

In line with this and for this research, the researcher himself corroborated his story with other family members who attested to its authenticity. As for the respondents, other siblings were encouraged to be present at the interviews to confirm the facts stated. Where an interview was refused and a respondent provided a written story, a request was made for the story to be verified by other members of the family to ensure the accuracy of the facts.

#### **6.8.4. Laxity in Ethics With respect To Others in the Researcher's Own Story**

This drawback arises because where a researcher is narrating his own story he is less concerned with the issue of confidentiality says Chang (2007). However, he forgets that others are also mentioned in his autobiographic rendering and the protection of their confidentiality is equally important in an autoethnographic study. Therefore his qualms are, since the prominent characters in the story are revealed, hiding the identity of the others closely linked to them is an arduous task. Nevertheless in autoethnography just as in other research pursuits, every effort must be made to ensure that the confidentiality of the others in the story is maintained, as a matter of ethics. In the current research, the respondents have been assured that the interviews will be conducted on a no-name or fictitious name basis; any reference to the person with a disability and the sibling is by way of a pseudonym.

#### **6.8.5. Mislabelling Autoethnography**

Chang laments that another weakness is that the autoethnography term is loosely used with reference to numerous methods of inquiry in the various fields of study. He fears



that this may confuse both the researcher and the readers. He suggests that the researcher should convey this information to the reader, clearly defining the context of which it is being used in this study, thus enabling the reader to differentiate this research from others which also entail the narration of one's own story such as an autobiographic account or other self-narration works.

The present study clearly indicates from the onset that although it begins with a storytelling method involving the difficulties endured by siblings of persons with disabilities, the objective is to analyse these problems, recognise the emerging patterns, draw inferences from the findings, and conclude whether a case can be made to advocate the introduction of tax relief which may help to mitigate the impact of these difficulties at least from a financial viewpoint.

## **6.9. THE USE OF AUTOETHNOGRAPHY IN ACCOUNTING AND TAXATION**

Doloriert & Sambrook (2011) eloquently proclaim autoethnography to be “more than a style of analytic writing”, recommending it as a “popular contemporary methodological approach within evocative interpretivism” (p.584). They are aware, however, of the resistance faced by autoethnography; the resistance is especially evident in post-graduate dissertations and theses where it faces the criticism of narcissism (Coffey, 1999), to the extent that some supervisors of these dissertations and theses discourage its use altogether (Morse, 2002). Nevertheless this dampening shroud of pessimism is lifted when they observe that “doing an autoethnographic PhD within a traditionally positivist business school can be more challenging than doing an autoethnography within disciplines that are more open to and accepting of contemporary ethnography approaches (e.g., social sciences, communications, health care, and illness)”, because

they sincerely believe that “critically sharing our experiences of doing autoethnography should help improve our practice, overcome challenges, and encourage others to choose autoethnography as a viable methodological approach” (p.584).

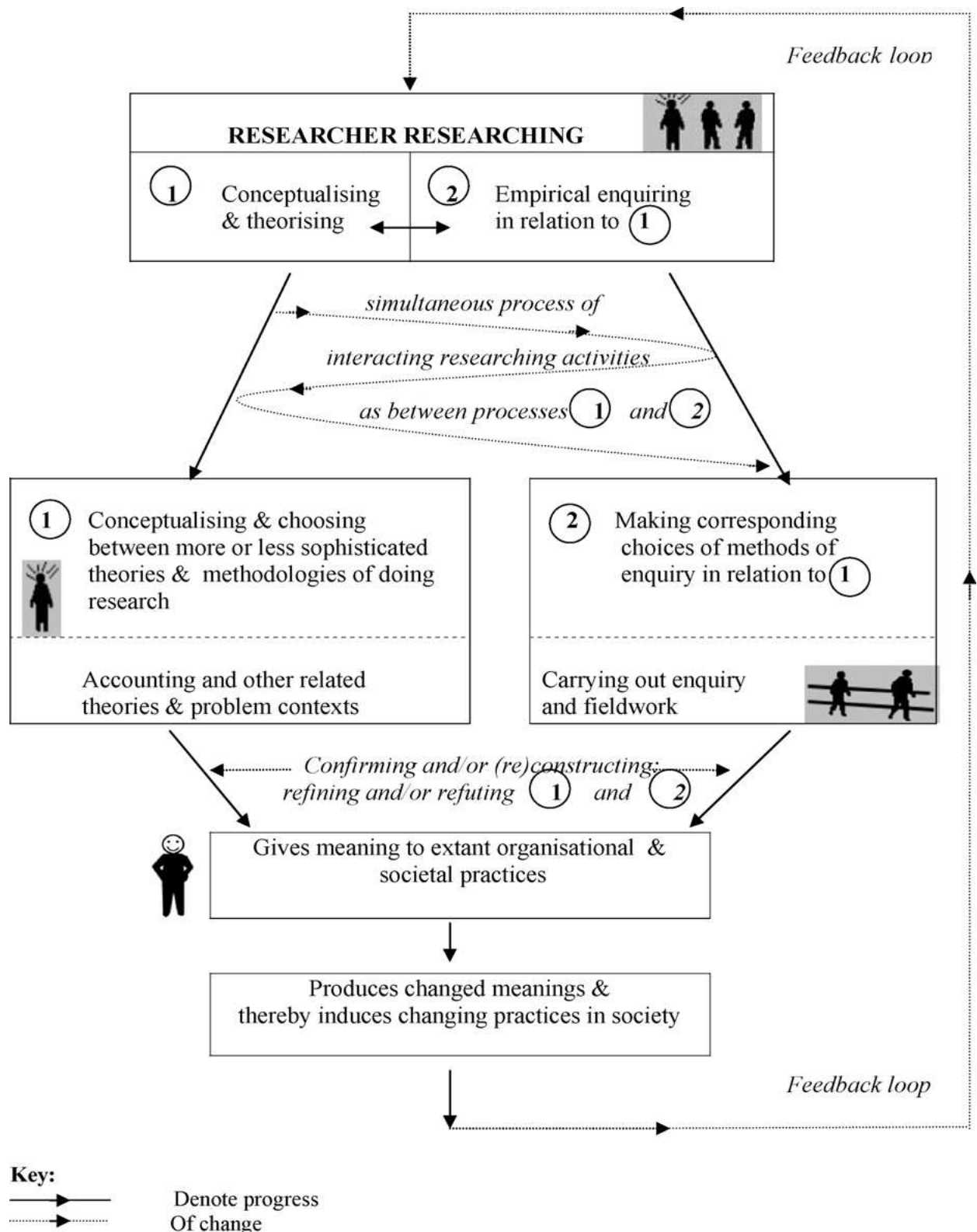
The use of autoethnography is not new, as detailed by Doloriert & Sambrook (2009), who noted that it appears in research in many fields: “from anthropology (Okley & Callaway, 1992); sports sciences (Sparkes, 2000; Holt, 2003); nursing and health care (Ellis, 1993, 1998)”; to more niche contributions; “design (Duncan, 2004); creative art (Bochner and Ellis, 2003); and political science (Burnier, 2006)” (p.28). Further in the field of higher education, the income provide examples of “autoethnographies of early career lecturers (Holt, 2003; Pelias, 2003), senior academics (Sparkes, 2007), doctoral students (Humphreys, 2005), student-supervisor and supervisor-supervisor relationships (Sambrook et al., 2008) [and] colleague related – relational ethics (Vickers, 2002; Medford, 2006; Ellis, 2007; Etherington, 2007)”.It extends further to “research-areas-as-autoethnography (Ellis & Bochner, 2003, an autoethnography of writing a text book chapter on autoethnography) [and]an autoethnography on learning about autoethnography” (Wall, 2006, p.28).

Closer to home, in the field of accounting, we have Davie (2008), who provides classic arguments in support of the use of autoethnography as a methodological tool. She commences by stating (at pp.1054-1055) that a tide of strategic change has permeated through the halls of accounting research by “theorising accounting in action as a social phenomenon in specific situations.” Engaging a critical perspective, it seems to pursue “alternative explanations” to “the philosophical and theoretical basis of accounting as a subjective, independent, representational and technocratic pretensions.”

She continues to lament that “little effort has been expended in providing lived experiences of how and why these choices of methodological themes and theoretical frameworks are made” (p.1055). She opines that “doing research in accounting as social science involves reflexivity.” To achieve this, she suggests a “close and extensive interaction between the researched and the researcher(s) and a continuous act of exploring multiple realities . . . [whilst attempting] to arrive at a synthesised meaning and explanation for the multiple accounts of the participants’ private and generally available knowledge” (p.1072).

She recognises further that “theory construction is an active, dialectical and continuous process of de-puzzling and winnowing of the empirical”, which involves “a complex process of identifying similarities and explaining variations and contradictions so as to construct stories, themes, linkages of (changes in) economic and social structures.” To this end, she concludes that “the theory in this respect connects that which are observed and made sense of to a broader body of knowledge whilst the methodology defines the way in which this can be achieved”(p.1072).

This whole “process of knowledge production” is vividly depicted by her in the diagram labelled as Figure 1.1 below. Here she suggests that “the social processes of knowing and knowledge construction involve theoretical, methodological and methodical choices for linking epistemology with ontological experiences . . . because social enquiry is an exploratory process that is heavily influenced by ones personality and background as well as the biographies of those involved in the research process” (p.1074).



**Fig. 6.1** *The process of knowledge construction and of inducing change in a society's practices through research (Davie, 2008).*

Davie (2008) notes that “the making of knowledge is not value-free and worries about bias-free research outputs and illusions about objectivity are research entrapments that

frustrate new knowledge from emerging” (p.1074). She advocates that “accounting (auto) ethnographies can make a significant contribution to our understanding of contextual experiences of producing knowledge and of the politics of academic capital” (p.1075). She quotes Thomas (1993) who reminds us: “there is always room for honest intellectual disagreement over what constitutes ‘something better’, but even these debates, for critical scholars, are part of the process of knowledge production” (p.70).

A search of literature in established academic journals did not reveal any autoethnographic studies being undertaken in taxation. Therefore this study, which evokes an autoethnographic approach, contributes significantly to literature because it pioneers an autoethnographic attempt at undertaking a study in the field of taxation.

An adoption of the autoethnographic approach was prompted by the nature of this study. Although taxation is per se is a quantitative discipline but this research addresses a qualitative aspect in taxation which entails a representation of feelings, emotions, psychological facets and also the participants’ religious attitudes, which negates the use of quantitative methods. However, even amongst the qualitative ones, autoethnography stands out as the obvious choice as the researcher himself has experienced being a sibling caregiver for a disabled person.

## **6.10. CONCLUSION**

The chapter discussed the research methodology and the research design employed in the current study. Autoethnography has been clearly shown to be the methodology most suited for this study because it “confronts dominant forms of representation and power in an attempt to reclaim, through self-reflective response, representational spaces that

have marginalized those of us at the borders” (Holt, 2003). This study involves the experience of the researcher (as a sibling of a person with a disability) being used as a launching pad for the generalization to a wider spectrum of similar experiences by others that demonstrate a whole vista of congruent yet diversified feelings, emotions, sentiments and reactions. This has been formulated as a consolidated platform to appeal for the introduction of tax relief for siblings of persons with disabilities. The next chapter discusses the research design adopted to collect the “data” and argues for the validity and reliability of autoethnography.

## **CHAPTER 7**

### **RESEARCH DESIGN**

#### **7.1. INTRODUCTION**

Research design is defined by Creswell (2005) as the “procedures for collecting, analysing and reporting research”; it does not vary tremendously irrespective of the paradigm chosen. Chang (2007) explains that similar to other research processes, autoethnographic study also entails the collecting and analysing of data followed by an interpretation of the findings and culminating in the writing of the report. Nevertheless, this method requisites an active involvement through participation, observation, interviewing people, reviewing documentation and performing a triangulation of the database and the contents with view to analyse and interpret the emerging happenings, actions and feelings to facilitate the writing of the autoethnographic report.

However, Chang (2007) clarifies that research using a qualitative approach does not segregate the above mentioned processes i.e. the process of collecting, analysing and interpreting data is all interwoven and collaborative with each other and conducted to some extent simultaneously. It is this interactive display that culminates in the autoethnographic report. (Chang, 2007).

We shall commence our discussion with a review of the elements of validity and reliability, which are fundamental to the acceptance of a research study.

## **7.2 VALIDITY AND RELIABILITY**

As Silverman (2000) points out, it would be futile to conclude a study if the researcher is unable to demonstrate to the audience that adequate procedures were undertaken to ensure the reliability of the study methods and the validity of the conclusions reached.

### **7.2.1. What is Validity and Reliability**

Watson (2009) explains that “validity concerns the truthful representation of the object of research.” Silverman (2000) simply calls it “another word for truth” while Denzin (1997) describes “a text is valid (legitimate) if it is sufficiently grounded, triangulated, based on naturalistic indicators, respondent validation, carefully fitted to a theory, comprehensive in scope, credible in terms of member checks and so on.”

McKinnon (1988) states that “validity is concerned with the question of whether the researcher is studying the phenomenon she or he purports to study . . . [and] is impaired if the design and/or conduct of the research are such that the researcher is unintentionally studying either more than or less than the claimed phenomenon.” Unfortunately, as all these characteristics “do not readily lend themselves to autoethnographic practices...this calls into question its legitimacy as a mode of research” (Denzin, 1997).

Reliability refers to “the degree of consistency with which instances are assigned to the same category by different observers or by the same observer on different occasions”



(Silverman, 2000). McKinnon (1988) states that “reliability is concerned with the question of whether the researcher is obtaining data on which she or he can rely [because] reliability may be impaired if the data are not independent of the ‘accidental circumstances’ under which they are gathered.”

Riege (2003) suggests that to confirm quality in qualitative research design in general, the “tests of confirmability, credibility, transferability and dependability” are “analogous to the concepts of validity and reliability in quantitative research.” His analysis of the corresponding terminology for adopting the quantitative and qualitative approach is detailed in the Table 7.1 below.

Table 7.1

Corresponding Terminology for Adopting the Quantitative and Qualitative Approach (Riege, 2003)

Qualitative	Quantitative	Remarks
Confirmability	Neutrality and Objectivity (i.e., Construct Validity)	This test assesses whether the interpretation of data is drawn in a logical and unprejudiced manner. That is, to assess the extent to which the conclusions are the most reasonable ones obtainable from the data.
Credibility	Internal Validity	It involves the approval of research findings by either interviewees or peers (as realities may be interpreted in multiple ways), in order to demonstrate that the inquiry was carried out in a way which ensures credibility.
Transferability	External Validity or Generalisation	This test is achieved when the research shows similar or different findings of a phenomenon amongst similar or different respondents or organisations that are achieving analytical generalisation.
Dependability	Reliability	The purpose of this test is to show indications of stability and consistency in the process of inquiry. The underlying issue here is whether the procedures or techniques used in the process of study are consistent.

Lincoln & Guba (1985) also link “dependability” (in qualitative research), to “reliability” in (quantitative research). This is endorsed by Clont (1992) and Seale (1999), as cited by Golafshani (2003).

### **7.2.2. Qualitative Research and Autoethnography: Some Criticism**

Opinions on validity and reliability are abundant. Lincoln & Guba (1985) argue that the “existence of validity automatically illustrates reliability”, whereas Patton (2001) regards them as “an essential component at the different stages of a qualitative study.” However, Stenbacka (2001) provides a dissenting opinion by stating that “reliability is founded on measurements and therefore, bears no relevance for a qualitative study.”

Attempts to discredit qualitative studies have sought ammunition from their validity constructs, which have been subjected to close scrutiny and critique (Cho & Trent, 2006). Attempts have also been made to compare them using quantitative standards (Wall, 2008) using the argument that qualitative studies lack objectivity, reason, and truth (Denzin & Lincoln, 1994, as cited by Wall, 2008).

The main criticism that qualitative studies lack objectivity is further expounded by Wall (2008) in the following ways: generally in social sciences, the researcher’s own values and subjectivities will intervene in his research work (quoting Bochner, 2000); the researcher’s decision in describing an event, and the extent of that description, are guided by his/her own ideas (quoting Wolcott, 1999), and based on presupposed assumptions and interests (quoting Stivers, 1993). Wall finally quotes Thomas (1993) to

argue that such studies compromise their scientific values by bowing down to passion, and they make unsubstantiated assertions which are strident but lacking in reason.

In the next section we look at the validity of such accusations.

### **7.2.3. Validity and Reliability in Autoethnography**

Autoethnography involves the experience of the researcher who in turn “values narrative truth based on what a story of experience does—how it is used, understood, and responded to for and by us and others as writers, participants, audiences, and humans” (Bochner, 1994; Denzin, 1989; as cited by Ellis et al., 2011). The researcher “tells a story that allows readers to enter and feel part of a story that includes emotions and intimate detail and examines the meaning of human experience.” It allows readers “to feel the dilemmas, think with a story rather than about it, join actively with the author’s decision points” (Ellis & Bochner, 2000, as cited by Wall, 2008). She continues that the readers “become co-participants who engage with the story line morally, emotionally, aesthetically, and intellectually (Richardson, 1994, as cited by Wall, 2008). In the world of traditional science, objective distance seems to protect researchers and readers from the emotional and intimate details of human lives (Muncey, 2005, as cited by Wall, 2008).

Pearce (2010) aptly supports the recalling of personal experiences as a basis for understanding a situation, and provides a foundation for expanding that understanding to the society of which he is a member (citing Ellis, 1999, 2004). He further argues that

the autoethnographic account bridges the divide between the individual and society (citing Mitzal, 2003).

Acknowledging the fact that the description of an experience will nevertheless contain some minor omissions, Ellis (1999) lucidly illustrates that the purpose of autoethnography extends beyond the accuracy of the facts to a plan of displaying how it affected the researcher, what significance it held for him and describes the implications for him and how such a portrayal invites the reader to immerse himself in this very experience. Pearce (2010) too, in citing Smart, (2007), acclaims that a comprehension of the personal self is a reflection of the experience at large in society.

When questioned about validity, Ellis (1999) explains that the definition of validity itself is ambiguous because the portrayal of truth itself can be different from a linguistic viewpoint. Thus, as long as the story told in the autoethnographic account invokes a sense of credibility and authenticity in the minds of the readers and enables them to relate to other people having the experience being described (and this provides an opportunity to improve all their lives), then validity prevails.

Knowledge itself evolves from learning from an experience explains Stanley (1993), as quoted by Pearce (2010), in her own personal writings about the illness and eventual death of her mother. One acquires knowledge of a particular area through enquiring about it and further by experiencing that very situation or hearing the account of a person who has experienced such a situation. Therefore, she argues that an autoethnographic account has both an ontological support because it recalls the personal

and social relation of the individual plus an epistemological backing on the grounds of how the knowledge was acquired.

In terms of reliability, Ellis (1999) states autoethnography cannot be subjected to the traditional notions of reliability because it represents a narration of our personal experiences involving an exercise to bind the present situation with a memory of the past and the anticipated future. Nevertheless she acknowledges that a check for reliability can be performed by allowing a review of the work done for their comments or additional information or just a point of view.

In quantitative research, the capability of a study to be tested and evaluated was reliability. Therefore, says Golafshani (2003), when translating reliability in a qualitative paradigm the test is one of evaluating quality i.e., does the study enable the reader to understand an initially perplexing or baffling phenomena (citing Eisner, 1991). He further points out that in quantitative studies reliability embraces the ability to explain, but in qualitative research the test is can it generate an understanding of the situation at hand? (citing Stenbacka, 2001).

Relating one's own life story creates a channel for comprehending and in consequence claiming to have "knowledge of wider social relations" (Ellis, 1999, 2004). Therefore, an account of autoethnography bridges the gap "between the individual and the collective by acknowledging that, individual 'embodied' remembering is always 'embedded' in a social context" (Mitzal, 2003).

The claim of validity in qualitative research is further supported by Cho & Trent (2006) in two ways. In the “transactional approach” they argue that what could be closer to the truth than the actual account of experiences, feelings, values and beliefs by the researcher himself or the person being researched. Second, from a transformational validity viewpoint, they argue that validity prevails where the study can bring about a change in society (i.e., the change advocated by that study), and where there is an evident element of progress, emancipation or at the least a deeper understanding of the situation being described in the study.

In the current study, the motivation and inspiration arose from the researcher’s own experience as a sibling of a disabled person. Any concerns, however, about a lack of validity and reliability can be laid to rest with the Cho & Trent (2006) prescription that there must be “a progressive, emancipatory process leading toward social change.” The prescription is met in that the objective of the current study is to encourage the evolution of the tax system by proposing tax relief or rebates for individuals taking care of disabled siblings. The study also complies with their criterion of “a critical element in changing the existing social condition” because the study recommends a change from the current practice of providing tax relief only to parents and children of persons with disabilities.

#### **7.2.4. Sampling in Autoethnography**

O’Reilly & Parker (2012) argue that the procedures for “the selection of respondents” differ between quantitative and qualitative research because “the purpose” of the latter is “not to count opinions or people” but rather to “explore the range of opinions and different representations of an issue” in line with its concern with “the richness of

information.” They cite Gaskell (2000) in confirming that the choice of the number of participants “depends on the nature of the topic and the resources available.” Additionally, “the focus is less on sample size and more on sample adequacy”, citing Bowen (2008) who further argues that “adequacy of sampling relates to the demonstration that saturation has been reached.” In conclusion, they cite Marshall (1996) in holding the view “that the researcher should be pragmatic and flexible in their approach to sampling and that an adequate sample size is one that sufficiently answers the research question.”

A good example to illustrate that sometimes a small number of respondents is sufficient, even in an autoethnographic study dealing with accounting, would be Jane Gibbon’s, “Understandings of accountability: an autoethnographic account using metaphor” (Critical Perspectives on Accounting 23 (2012) 201– 212). Here she uses “two conceptual metaphors, a jigsaw and a garden,” to explore and derive insights into the concept of accountability in relation to developing two social accounts for not-for-profit organization. Using “metaphorical conceptualization through a personal account” and reflecting on her own experiences, she acknowledges the complexities involved when dealing with accountability in practice and this cleared her path to her ultimate goal i.e., the recognition that in preparing the social accounts for not-for-profit organizations there is a need to be aware of and to steer away from, the dominance of the calculative factor combined with the influence of certain social elite and instead give due respect to the complexities of accountability and the non-calculative factors.

A search of published literature did not reveal any autoethnographic studies conducted in the field of taxation therefore, a comment cannot be made in respect of sample size for an autoethnographic study in taxation.

### **7.3. THE ‘DATA’ COLLECTION OR CAPTURING THE SALIENT EXPERIENCES**

In an autoethnography, as is the case in this study, the process of data collection generally commences with the researcher’s own story which would have provided the stimulus for undertaking such a study. However, the research would be extended to encompass the stories of other members of the “family” to provide creditability to the researcher’s own story, to illustrate the commonality of such experiences amongst others in the “family”, to justify the undertaking of such a study and to prove beyond doubt that the proposed changes are in tandem with the views of other members of the “family.”

#### **7.3.1. My Own Story**

Ellis et al. (2011) clarify that autoethnography is in essence an autobiography written ethnographically with the author recollecting about and discerningly narrating the experiences in his life. However, using hindsight, the past experiences are drawn together to facilitate the structuring of a story, although the author never harboured the intention to publish these experiences when he lived it. (Bruner, 1993; Denzin, 1989, Freeman, 2004, as cited by Ellis et al., 2011). The story is usually pieced together from memory. Chang (2007) describes memory as a comrade in research permitting admission to a data source inaccessible to others, assisting in shaping, selecting and limiting in accordance with our needs but yet remains an adversary fading with time coupled with clouding resulting in loss of details. Therefore, since sole reliance on memory is generally insufficient, it is usually augmented with the narrator seeking aid by conducting interviews, perusing journal records and photos (Ellis et al., 2011).



Ellis et al. (2011) also state that when writing your own story, most people will write about unforgettable times that had influenced the route pursued by their life, events that have made them stop and think about it and because of which their lives had been steered into another path. They refer to these as “epiphanies.” Having understood the story of the researcher, data collection is expanded to include the stories of other members of the same “family” since “autoethnography is a self-narrative that critiques the situatedness of self with others in social context” (Spry, 2001, as cited by McClellan, 2012).

One cannot forget that although in autoethnography the researcher does “engage in introspection and emotional recall to display the complex notions of the topic researched”, but this must establish a bond linking “the autobiographical and personal to the cultural and social” (McClellan, 2012, in citing Ellis 2004). The whole exercise is “to describe and systematically analyse personal experience in order to understand cultural experience” (Ellis, 2004; Ellis, Adams, & Bochner, 2011; McClellan, 2012). The next section deals with the procurement of the “other stories.”

### **7.3.2. The Stories of Others**

Ellis et al. (2011) explain that in undertaking an autoethnographic study, researchers, in retrospect, select “epiphanies” that have arisen due to their association with the particular group or family and/or embracing their characteristics. In addition, Creswell (2005) discusses critical ethnography which seeks “to include an advocacy perspective to ethnography” whereby the researcher “is interested in advocating for the

emancipation of groups marginalized in our society” (which in this study would be siblings of persons with disabilities). Therefore, the researcher cannot be satisfied with just his story but must be able to link it to stories of others who are members of the same “family”. He must study the lives of others who are taking care of disabled siblings, seek out common traits and characteristics and be able to effectively convince the reader that his predicaments are not an isolated affair but instead a generalisable problem affecting all members of the “family”.

To find the other members which would be relevant to this study, a purposeful sampling was undertaken, whereby an individual was chosen because he “illustrates a feature or process in which we are interested” (Silverman, 2000). Creswell (2005) explains that “in purposeful sampling, researchers intentionally select individuals and sites to learn or understand the central phenomenon.” The next step, he states, is “to identify your sampling strategy and be able to defend it.” In this study, the strategy adopted was the homogeneous sampling strategy whereby the “researcher purposefully samples individuals or sites based on membership in a subgroup that has defining characteristics.”

### **7.3.3. Data Collection Activity**

The data collection activity “continues throughout the research process with different intensity at different points” (Chang, 2007). Chang (2007) refers to data as “field texts” as she declares that this “describes more accurately what autoethnographers do.” Data collection commences with seeking out appropriate research sites, making clear the objectives of the study, seeking the approvals of the relevant authorities at those sites and proceeding with the purposeful sampling activity. The assembling of an information

base for this study began with documentary evidence discussed below and structured interviews using open-ended questions. The activity commenced with the gathering of “members” (i.e., siblings taking care of persons with disabilities).

#### *7.3.3.1. Selection of “Members of the Family”*

Perera (2005) complains that a major obstacle in the path of field researchers is “getting access to a suitable research site.” In many cases, the apathetic attitude arises from a lack of understanding of, and the absence of concern with, the objective of the study. This is aggravated by the fear of breaching confidentiality, and general worries about the sensitivity of the whole affair. By research standards, researchers “are expected to minimise sample selection bias when selecting the research site [but] because of the limited opportunities available to them, researchers often select those organisations that are willing to cooperate, those that have a unique situation, or those who needs outside help” (Perera, 2005).

In this study, in line with the intention to do purposeful sampling, requests were sent out to fifteen nursing homes, old folks’ homes, associations related to persons with disabilities to first identify if any of their inmates or members were cared for or financially sponsored by a sibling, and then to be able to interview the sibling. As no responses were received, appointments were made to personally see and appeal to the persons in charge of the organizations. The response was disappointing, with many rejections in spite of emphasising that the study seeks to address an inequity in society and intends to advocate for a change to help transform society. The main reason quoted by those who refused to participate, in spite of the promise of anonymity and the profound emphasis on the merits of the study, was that in their opinion, even speaking

of their disabled kin would breach the fundamental ethics of privacy and secrecy. One group based its refusal on a rather unusual religious outlook saying that such disclosures would nullify all the goodness that they had harvested by taking care of the disabled siblings and jeopardize their chances of achieving heaven/nirvana etc. Another viewed the practice of taping the conversation suspiciously and commented that the maintenance of anonymity does not provide a guarantee that their voice will not be recognised by others. The last group however, acceded to the researcher merely taking notes during a discussion with the assurance that the final copy would be provided to them for their concurrence of the accuracy of what was written. These views are discussed in the section on field notes presented below.

After relentless endeavours, a favourable response was received from one nursing home that referred the researcher to the two sponsors of their inmates who were also their siblings, after having obtained their express permission for the information to be released. Both the respondents were of the same race but different religion.

As the response was weak, with mainly respondents of the same race/religion being introduced, the researcher attempted to use snowball sampling strategy instead. Creswell (2005) elucidates that this “proceeds after a study begins and occurs when the researcher asks participants to recommend other individuals to study.” This is usually done “as a question during an interview or through informal conversations with individuals at a research site.” With this renewed effort, eight qualified respondents of the Hindu faith were obtained, with one respondent having two disabled sisters. Subsequently, an additional seven respondents with different racial and religious backgrounds were found, bringing the total number of participants to seventeen. The additional respondents included two Muslims, two Buddhists, two Christians and a

person with an undisclosed “personal religion.” Initially, the researcher was apprehensive about the inadequate number of non-Hindu respondents interviewed. However, as the themes emerged and were coded and categorised, the similarity of the responses was indicative of saturation as explained below.

Bowen (2008) explains that “data saturation or theoretical saturation is integral to naturalistic inquiry”, but Reilly et al. (2012) state that the latter was “developed [for] the approach of grounded theory” and so bears no relevance to this study. However, they advise that data or thematic saturation “are normatively taken to mean that data should continue to be collected until nothing new is generated; the point at which there are fewer surprises and there are no more emergent patterns in the data.” Bowen (2008) concludes that “saturation is reached when the researcher gathers data to the point of diminishing returns, when nothing new is being added.” He cites Charmaz (2003) who “explains that saturation calls for fitting new data into categories already devised”, and also Morse et al. (2002) who “point to the purpose of data saturation: ‘saturating data ensures replication in categories; replication verifies, and ensures comprehension and completeness’.” Dickson-Swift et al. (2009) interestingly point out:

*...it's not just about saturation of when you don't get new themes . . . it's about your saturation as well – how much you can actually take and I could not, could not have fronted for another one of those interviews.*

The next step was to determine how to obtain the views of the other “members of the family” with respect to the advocacy of tax relief for siblings of persons with disabilities. A taped interview was thought to be the most appropriate method of collecting the information. To ensure that the quality of the recording was high, the suggestions by Patton (1990) were strictly adhered to. The list of suggestions is detailed in Appendix A.

### *7.3.3.2. Taped Interviews*

Patton (1990) aptly describes the purpose of interviewing as “to find out what is in and on someone else’s mind . . . [and] . . . to find out from them those things we cannot directly observe.” He extends this to open-ended interviewing where he emphasises that the purpose “is not to put things in someone’s mind but to access the perspective of the person being interviewed.” Chang (2007) further explains that the tool of interviewing as a “vital data collection technique” because she says “the interviews provide not only outsider perspectives, but also external data to confirm, complement, or dispute internal data generated from recollection and reflection.” However, she is quick to caution that sometimes “face-to-face interview can hamper honest exchanges between interviewers...and interviewees.”

Patton (1990) discusses “three basic approaches to collecting qualitative data.” First, the informal conversational interview which “relies entirely on the spontaneous generation of questions in the natural flow of an interaction.” Second, “the general interview guide approach” outlines “a set of issues that are to be explored” but does not entail “a set of standardised questions...written in advance.” The third is the “standard open-ended interview” consisting of “a set of questions carefully worded and arranged with the intention of taking each respondent through the same sequence and asking each respondent the same questions with essentially the same words.” Silverman (2000) elaborates on the advantages of taping an interview. He first emphasises that without taping the researcher will not be able “to remember (or even note at the time) such matters as pauses, overlaps, inbreaths and the like.” He then notes the value of the tapes as undisputable evidence, plus “they can be replayed and transcriptions can be improved and analysis taken off on a different tack unlimited by the original transcript.” Finally, he talks of words uttered by others in the environment, which may bear relevance to the

study; this may be caught on tape but may be missed by a researcher desperately trying to keep up with the pace of the respondent's answers.

As this study was based on the specific objective of advocating for the introduction of tax relief for siblings of persons with disabilities, the third approach was held to be the most relevant one. The obvious benefit of this approach is that minimum "variation in the questions posed to interviewees...reduces the possibility of bias." However, the questions are not devoid of "clarifications and elaborations" and are complemented by "probing questions . . . placed . . . at appropriate places" (Patton, 1990). He delineates this approach's advantages as: 1) "the exact instrument used in the evaluation is available for inspection by decision makers and information users"; 2) "variation . . . can be minimised"; and 3) "the interview is highly focused" so the respondent's time is not wasted.

#### *7.3.3.3. Field Notes*

Many participants voiced reservations to having the interview taped, even with the assurance that it would be on an anonymous basis and the contents were purely for this study alone. The researcher therefore had to take field notes as open ended questions were posed to the respondents.

Lofland (1971) declares that field notes are "the most important determinant of later bringing off a qualitative analysis." The importance of field notes has also been emphasised by Anderson (2006), especially because of the researcher's dual role as "a member in the social world under study and as a researcher of that world." He also stresses the need for an "enhanced textual visibility of the researcher's self" which

“demonstrates the researcher’s personal engagement in the social world under study”, and also serves to “illustrate analytic insights through recounting their own experiences and thoughts as well as those of others.” Field notes also serve to augment the researcher’s memory of what was spoken by respondents and participants, as well as his own perceptions of the environment in which the interview was conducted, the emotional and psychological condition of the respondents and any other pertinent facts that bear relevance to the “data” collected.

#### *7.3.3.4. Written Interview Guide*

Chang (2007) also offers “other creative alternatives such as email survey or questionnaire compiled” which may allow the respondents to express their feelings more freely and provide more accurate answers because they have the leisure of adequate time to think thoroughly. Again, in this study, many participants voiced reservations to even participating in an interview out of concern that their voice would be recognised. However, they were willing to provide answers to open-ended questions in the form of an extended questionnaire which contained the same questions asked of respondents in a personal interview. The interview guide used in this study can be found in Appendix B.

For both the interviewees and those who obliged to fill in the interview guide, the ethical practices employed by Pearce (2010) were closely followed. All participants received “full details of the research [which clearly] outlined details about confidentiality and anonymity”, and which also included the research questions and research objectives. The participants were told “before and at the interview that they need only talk about what they felt comfortable with” and they were assured that they



had a “right to read and comment on the completed dissertation.” My involvement was restricted to “asking few direct questions”, which provided the participants “space to build and guide their own narrative.” However, where the participant/respondent had “difficulty knowing what to say without direct questions”, I “shared a little of my experience” purely for clarification purposes.

#### **7.4. DATA ANALYSIS AND INTERPRETATION**

As indicated in the preceding section, data analysis in qualitative research is generally not an isolated activity by itself but is conducted simultaneously and interwoven with the process of data collection. Stockdale (2003) suggests that “this is particularly true of the interview method of data collection where meaning, clarification and interpretation are continuous throughout the interview and subsequently.”

Although autoethnography traditionally involves only one’s own story, additional efforts were made in this study to include the stories of others who were experiencing a similar predicament, with the aim of “developing theoretical understandings of broader social phenomena.” An analysis of their views was undertaken because “some of the most important early efforts in autoethnography were undertaken by scholars with clearly analytic goals”, and because their views would provide added leverage to illustrate validity and reliability (Anderson, 2006).

Miles & Huberman (1994) define qualitative analysis as consisting of “three concurrent flows of activity; data reduction, data display and conclusion drawing/verification.”

#### **7.4.1. Transcribing Data from an Interview**

Data reduction basically involves selecting, focusing, simplifying, abstracting and transforming the data collected through interviews and field notes. In cases where permission was granted for taping, the immediate step taken at the completion of the interview was to replay the interview so that the respondent could concur with the accuracy of the issues discussed in the interview. The next step was to transcribe the contents with the aid of short notes that had been taken whilst the interview was being conducted. However, where the respondent did not allow the interview to be taped, reliance was solely on the detailed field notes taken throughout the interview. These were then transcribed into a proper format and were then shown to the respondents for verification of accuracy. Silverman (2000) cautions that “you must attempt to transcribe as much as possible of what is said and done and the setting in which it is said and done.” In this study, the basic details of the disability, the family background, the environment in which the person with a disability was cared for and the financial standing of the sibling were relevant factors that had to be known in order to fully understand the anguish, trauma and pain endured by the siblings.

#### **7.4.2. Coding of the Data Collected**

The analysis, commencing with coding, was carried out using the NVivo (Version 8) software package which “offers many new features to enrich qualitative analysis” and that has “enhanced the capacity of researchers to achieve new levels of analytic integration of qualitative...data sources” (Bazeley, 2002). Stockdale (2003) states that this method “allows for triggers or categories of interest in the text to be coded and used to keep track of emerging and developing ideas.” She adds that “these codings can be

modified, integrated or migrated as the analysis progresses ... [for] ... the generation of reports.” She cautions, however, that although “NVivo, has advantages in handling a large amount of data over a long period as the research unfolds”, it nevertheless does not replace “the need for the researcher to remain in touch with the research data and to maintain adherence to rigorous principles.” This is necessary as “qualitative data analysis is not [just] a mechanical procedure” per se, but also includes the “dynamic, intuitive and creative process of inductive reasoning, thinking and theorizing” (Darmody & Byrne, 2006). It “involves hours spent with the data exploring emerging themes and concepts and the links between them” (Darmody & Byrne, 2006).

However, in an autoethnographic study, NVivo software was only used to code the different themes arising from the “other stories.” The coding process started by uploading the transcripts prepared with Microsoft Word into the NVivo software. Then, as each sentence was read, its essence was captured in the form of an emerging theme and registered with a particular node in the software. Sometimes a particular node was further segregated into sub-nodes so that certain words of the respondents could be more accurately categorised into a sub-theme. Once one transcript had been fully codified, with each emerging theme being successfully associated with a particular node or sub-node, the process was repeated with another transcript until all of the transcripts had been processed.

The nodes and sub-nodes used to classify the emerging themes are detailed in Table 7.2 below.

Table 7.2  
Nodes and Sub Nodes used in NVivo Coding

1. Character description of the disabled person
2. Cost factor
3. The difficult moments in caregiving
4. The impact on the caregiver's work
5. Influence on sibling caregiver's life
6. Sacrifices made by the sibling caregiver
7. Placement at home or institution
8. Religion
9. Current welfare practice in Malaysia
10. What welfare benefits will be useful
11. Government's concentration – big companies versus the man on the street
12. Would a tax relief have been useful?
13. Who should get the relief?
14. Response to Singapore having a tax relief for sibling caregiver

That basically concluded the activity of data reduction and paved the way for data display.

#### **7.4.3. Data Display**

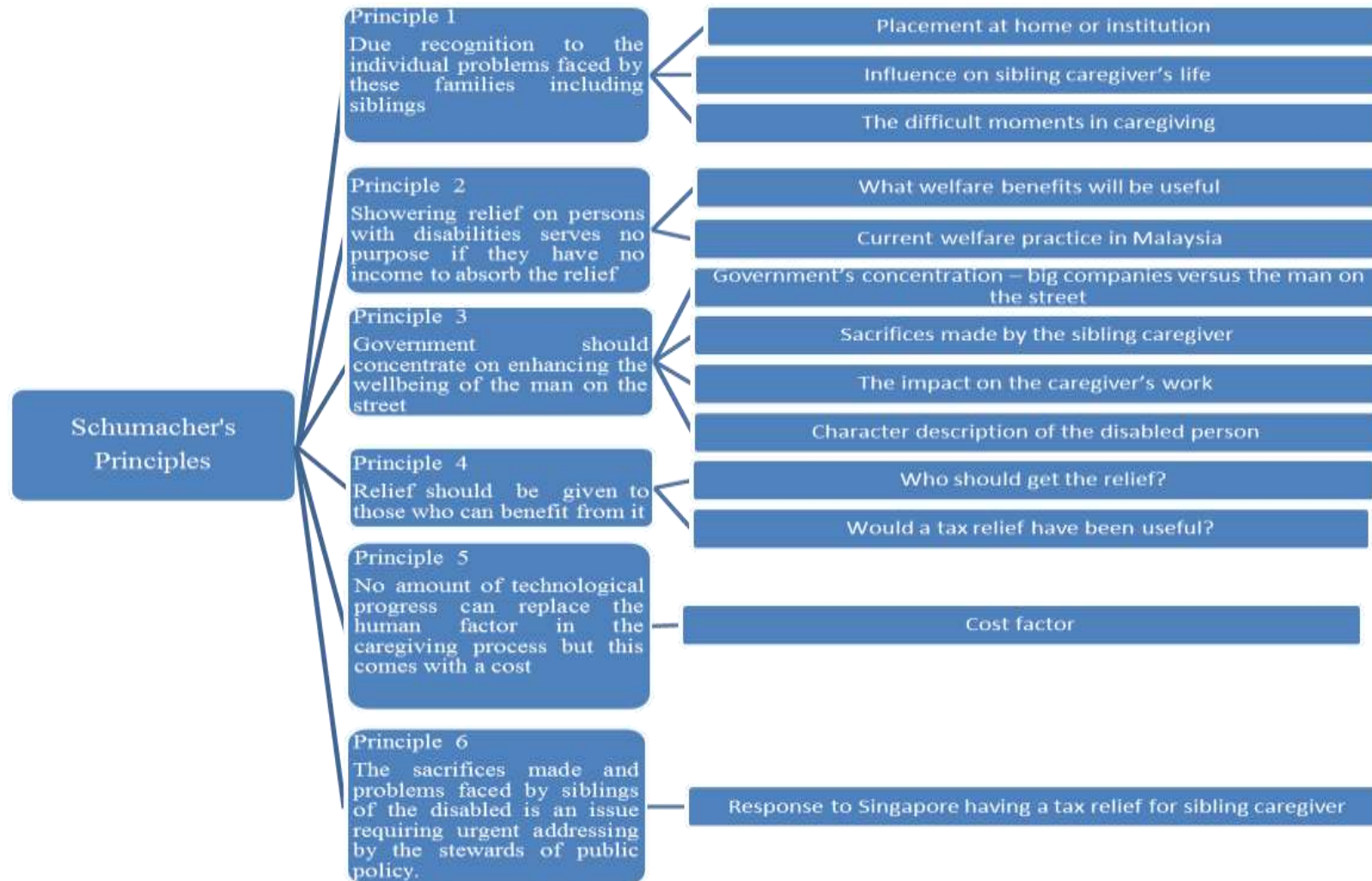
Miles & Huberman (1994) describe data display as an organised, compressed assembly of information that permits conclusion drawing and verification. Although they state that “humans are not very powerful processors of large amounts of information”, the detailed analysis of the words spoken or written by the respondents was performed manually as it required an understanding of their emotions, feelings and perspectives when giving their views. Also, in many cases the researcher was at the scene of the interview and was therefore able to “experience” the feelings of the respondents as they spoke. In any event, the analysis involved only seventeen caregivers talking about eighteen siblings so the analysis was not overwhelming for the researcher.

This leads us to the final step of conclusion drawing and verification.

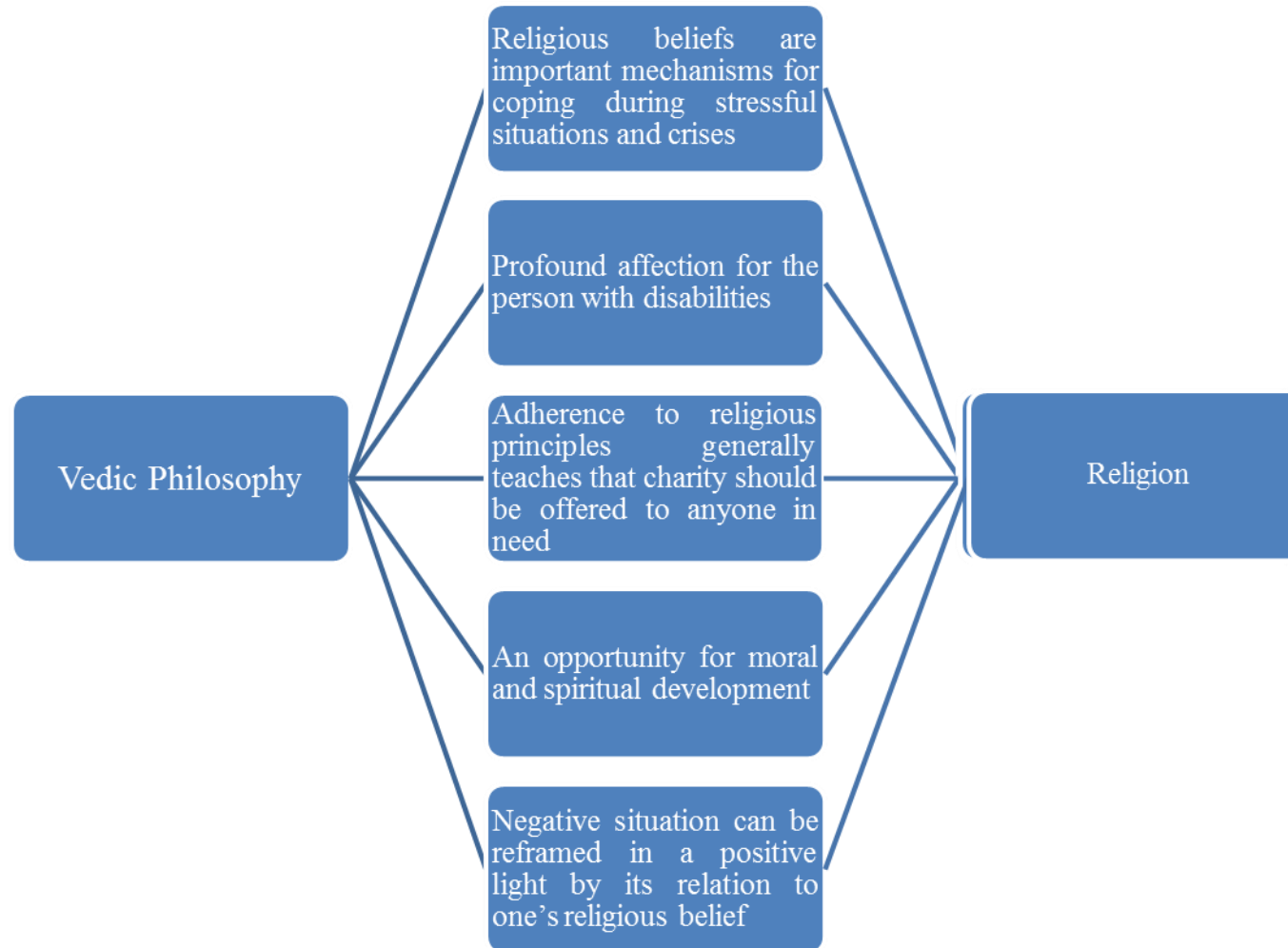
#### **7.4.4. Conclusion Drawing and Verification**

The last activity is conclusion drawing and verification. Here the themes identified at the data reduction stage are matched with the principles enunciated by philosophy expounded by Schumacher (Table 7.3) and enshrined in the Vedas (Table 7.4).

**Table 7.3 Relationship of Emerging Themes and Schumacher**



**Table 7.4 Relationship of Emerging Themes and Vedic Philosophy**



The display of the “data” furnished an opportunity for the researcher to structure an essay on each emerging theme. This involved comparing and contrasting the responses of the different siblings and identifying any logical relationship, recognising any particular reason for a disparity in responses and juxtaposing contradicting views and opinions. This work ultimately facilitated an interpretation and, in consequence, the formation of a substantiated conclusion.

## **7.5. CONCLUSION**

This chapter discussed the research design employed in the study. Having established the use of autoethnography as an acceptable research methodology, the chapter described the process of data collection and gathering salient experiences. The researcher’s own experience of caring for a disabled sibling was collected first, followed by the collection of the experiences of respondents, each of whom had a different story to tell about sibling caregiving activities. The data was analysed and interpreted, and conclusions were drawn and verified. The next chapter discusses the researcher’s own story.



## **CHAPTER 8**

### **STORIES: MINE AND OTHER SIBLING CAREGIVERS**

#### **8.1. INTRODUCTION**

This chapter deals with the life story of my disabled sister who ultimately succumbed to cancer, and how my life and the lives of our other siblings had been intertwined with hers. The story provided the impetus to undertake this study due to a series of realisations and experiences encountered throughout our lives, and the hunch that this may be similar in the lives of many others. Following this introduction is my sister's life story. It details the onset of her disability and then explains the second blow when she was afflicted with cancer. This is followed by the disclosure of how this autoethnographic study was inspired and motivated, including details of how the caregiving responsibility had affected my life and that of my other siblings. Subsequently the stories of seventeen other sibling caregivers are discussed to enhance the rigour and authenticity of this endeavour. The chapter closes off with a conclusion.

#### **8.2. THE BIOGRAPHY OF MY SISTER – ONSET OF THE DISABILITY**

The story unfolds with a quick look at my sister's early life, and how an unanticipated fall and a wrong decision landed her in the ranks of persons with disabilities.

### **8.2.1. The Early Stage**

My sister was born on 19 January 1949. Our father worked as a chief clerk on a rubber estate and our mother was a housewife. The third child in a family of eight (including the parents), she had a happy childhood mingling and playing with the numerous children on the rubber estate. She attended the Junior Methodist Girls School in Kuala Lumpur from 1956 to 1961 and then proceeded to Form One at the Senior Methodist Girls School, also in Kuala Lumpur. Although I had not been born at that time, in my later conversations with my parents and those who knew her, my sister was described as an intelligent and caring person and always bubbling with zealous enthusiasm.

### **8.2.2. The Agonising Fall**

In 1962, whilst in Form One, my sister had a fall while playing netball. Initially, it was mere aches and pains but one particular pain at the lower end of her back was rather excruciating. The fear of going to a doctor forced her to bear it without complaining, a move she would regret for the rest of her life. A few weeks later, she was down with a bout of chicken pox.

Whilst having the chicken pox one fateful morning, as she woke up to go to school she found that she could not get up. Not only could she not feel any sensation in her lower body, but she could not even raise her body up from the bed. She screamed for help, drawing our parents frantically to her room. They found that she could only move freely from the neck upwards whereas there was limited movement in her upper body and none at all in the lower part. In our culture, during the period when a person is having chicken or small pox, the person should not see anyone outside the family. My belief is

that possibly it was an ancient practice to inhibit the spread of the disease, but the practice was given religious connotations to ensure that it was followed. Further consultation with a medium served to confirm that the practice was to be followed and that she should not be brought to a doctor in this state. Once the chicken pox had receded, she was rushed to hospital. After a gruesome three month stay, she was diagnosed as suffering from paralysis from a blood clot in her spine, which the doctors stated was surgically unsafe to operate on and remove. The active 13 year old girl was now bedridden and unable even to attend to her personal hygiene needs without assistance.

### **8.2.3. A Ray of Hope**

During this terrifying journey, my pious parents had never lost sight of the Lord's benevolence. They kept faith that as all doors towards her recovery were being slowly shut, the Lord would open a window. And He did. Correspondence with the doctors at Kottakkal Arya Vaidya Sala (a century old traditional medicine institution in Kerala, India) revealed that remedial action was possible.

However, they could only cure my sister if she was brought there. This was impossible, since my father could not take such a long leave of absence from work, and my mother could not leave the other small children at home and follow her. Most of all we could not afford it. Alternatively, they suggested that they could send the medicines over with detailed instructions on how they should be administered, and we could "treat" my sister at home. However, they could not guarantee a full recovery. With no other way out, my parents opted for this alternative, purchased the necessary medicines, herbs etc., and administered them to her strictly in accordance with the prescribed instructions (which

also entailed the preparation of special food which had to be consumed during that period). Though it took a toll on my parents, especially my mother since she also had to take care of the younger children (including the researcher), she nevertheless dutifully followed the instructions. Her efforts finally bore fruit when my sister was ultimately able to sit up, feel sensations in her upper body and, slowly over time, was able to attend to her personal matters with no external assistance. However, her ability to walk never returned.

#### **8.2.4. Life Nevertheless Goes On...**

Through the years, and although unable to walk, my sister was able to drag herself on her seat throughout the house and also had a wheelchair. Although it could not be manoeuvred through the rooms of the house, it at least enabled her to sit at a table to have her meals. She did not remain idle, but instead kept herself busy helping out with the household chores such as cutting vegetables, sewing (with a modified sewing machine) and caring for her younger siblings; teaching them, combing their hair, dressing them up and putting them to sleep.

Accepting her fate, she continued to live in this condition watching others progressing with their lives knowing that hers had reached a plateau. Nevertheless, she was an asset to our parents in their twilight years: when the other children had flown the coop in search of lucrative endeavours, my sister was with them and assisted them in many ways. She attended to phone calls, gave insulin injections to our diabetic mother, read the newspapers for our father when he underwent an eye operation, made garlands for their daily prayers and handled an unending list of other things. We, the siblings, made sure that she did not feel useless, and all contributions to the family were channelled to

her. Our sister literally administered the financial affairs of the family (e.g., she. settled all the bills, determined what groceries were to be bought and when, and even ordered the vegetables by phone giving the researcher sufficient funds to collect and pay for them).

This continued on for 40 years. My father and mother passed on in 1995 and 1997 respectively, but my sister still had her responsibilities to “run the family” and that kept her totally occupied. However, fate was determined that this complacency should end and dealt her a further blow in 2002 when it was discovered that she was suffering from cancer of the rectum.

### **8.3. THE BIOGRAPHY OF MY SISTER – THE SECOND BLOW**

The series of events associated with the cancer involved extensive medical treatments, surgical operations and other forms of therapy interventions best described by a medical person. In view of this, for this section, I interviewed my eldest sister who is a consultant surgeon at the Gleneagles Intan Medical Centre. This is her story.

#### **8.3.1. The Discovery of Cancer**

In July 2002, she complained of passing blood and mucus with her stools. I examined her and was shocked to find that she had a large growth in her rectum. She was advised to go to the hospital but as a paraplegic she was reluctant to be admitted to hospital. She opted instead for Ayurvedic treatment, which cost me about RM 1,000. As there was no improvement in her condition, I had to take her by wheelchair to Gleneagles Hospital,

which is about 30 kilometres from our house, for admission. A colonoscopy and rectal biopsy were done on 11 September 2002 and it confirmed rectal cancer.

As a doctor in the family and an elder sister, I had the unpleasant task of breaking the bad news to her and the family. The whole procedure of admission and colonoscopy cost RM 5,000 not to mention the psychological trauma and stress of the whole episode which affected my earning capacity (loss of income) for a few days.

She was readmitted on 23 October 2002 for surgery to remove the growth and this resulted in the removal of the whole lower part of the colon and rectum, creating a side opening called a colostomy for the evacuation of faeces. She was discharged from hospital after 10 days and the bill was RM 20,000.

### **8.3.2. Home Care**

Her home care was done by me and a maid, and daily cleaning of the colostomy and dressing was done by me assisted by a maid whom I had employed to take care of her. From Monday to Saturday, I had to rush from the hospital during lunch hour to do the colostomy care. The distance from the hospital to home was about 30 km and this entailed loss of time and again earning capacity. I did this for a month and as it was too exhausting, I hired private nurses to do the colostomy care from Monday to Friday. The private nursing cost RM 200 per visit and this excluded all the surgical material required for the dressing, the colostomy bags, the fluid-resistant pads etc. The whole cost for the 4 months was RM 8,000.

### **8.3.3. Radiotherapy and Chemotherapy**

My sister was advised to have radiotherapy and chemotherapy at Gleneagles Hospital. The radiotherapy was given from 2 December 2002 to 7 January 2003. As she was a paraplegic, my brother (the researcher) had to carry her to the car and drive her to the hospital every day for about 6 weeks, at a distance of 60 km back and forth. I took care of her during radiotherapy which again affected my job.

The cost of the radiation therapy was RM 7,000. My sister unfortunately had a severe reaction to radiotherapy, and her whole lower spine, buttocks and private area were burnt and excoriated. She also developed a bad bed sore. She was admitted again to hospital for dressing and wound care. As the spine was affected by the radiation, she had another operation for 11 hours. This was a spinal laminectomy and was done on 6 December 2003. The histopathology, showed severe radiation changes in the bone, lower spinal column and skin. The admission, operation and dressing costs came to RM 40,000. Chemotherapy was started on 30 December 2003 for 6 courses. A chemo port was inserted on 28 December 2003 and cost RM 5,000.

My sister only took 3 courses of chemotherapy as she could not tolerate the side effects. This admission together with the chemotherapy cost RM 80,000.

### **8.3.4. The Final Lap**

She was well for two years but then on February 2005 she started passing blood from the vagina. She was again admitted to Gleneagles Hospital from 15 February 2005 for 10 days. A cystoscopy and vaginal examination showed that the cancer had recurred in

the vagina and extended into the bladder. As the bladder was blocked by the cancer she needed a nephrostomy (draining of the kidneys) first on one side, then on the other side. The nephrostomy dressing and change of the nephrostomy tubes had to be done by a doctor and again I had to rush to the house to do the necessary care. The whole cost of the nephrostomy, catheters, bags etc. came to RM 10,000.

In the meantime, the cancer was advancing and the whole lower back and abdomen were covered by cancer tissue. She now requested alternative therapy and was given acupuncture, Chinese traditional medicine, Reiki treatment and homeopathic medicine. All this cost RM 30,000.

My sister was readmitted on 7 August 2005 for renal failure and pulmonary complications. She succumbed on 10 August 2005 during dialysis for the renal failure. True, it is an irrecoverable loss, an unfillable void, but nevertheless a finale marking the end of an unspeakable tale of sorrow, pain and suffering. A time of mourning passed and then reality set in: life must go on, right?

#### **8.4. THE MOTIVATION FOR AN AUTOETHOGRAPHIC STUDY**

The story of my sister illustrates the various challenges facing a sibling taking care of a person with a disability or serious ailment. The salient features identifiable are detailed below.



#### **8.4.1. The Cost Factor**

At the time of tax filing, my eldest sister informed that over the three years the total costs incurred in treating and caring for our late sister were about RM 260,000. She asked: “can I claim a tax deduction for all the expenditure incurred on her, as we have a caring government?” My two and a half decades in tax practice prompted an immediate negative response, as I knew only too well that our tax system does not provide any relief for siblings, only for parents and children. Although I was speechless at first when she retorted with a vehement “but why?”, this question served to sow the seed of inquiry, planted the urge to address this inequality and placed me gently at the start of this research.

Of course, there are no regrets for spending what we did, as we wanted the best for our sister and feel comfortable that we had done our best for her. However, such expenditure on a parent or even a spouse or child (since cancer qualifies as a serious disease) would have qualified for a tax relief of RM 5,000 per annum, totalling RM 15,000 over three years. Unfortunately no relief is given to taxpayers taking care of disabled siblings. Although the deduction is relatively insignificant, it nevertheless feels good to have the government appreciate and recognise the contribution made towards a disabled or ailing person. Contributions of a sibling caregiver should be given due recognition by introducing tax relief for them similar to the relief we have now for parents, spouses and children

#### **8.4.2. The Psychological Factor**

Living with a disabled sibling is a complicated and mixed experience. Having been raised in an orthodox Hindu family, with parents who seemed to me to be the very epitome of piousness and religiosity, it was difficult to comprehend why a disabled child would be placed in such a family. The general response by my parents (which I now realise had the dual role of also fortifying the relationship between us siblings) was to say that we were the family that God had chosen to nurture this special child because of her distinctive needs, her vulnerability and her inability to perform certain tasks which we took for granted. Having accepted her as she was, the pre-cancer years did not produce any psychological strain; on the contrary, she was such an asset with her tailoring skills, her talent for making beautiful flower garlands, her remarkable aptitude and decision-making capabilities whenever a family problem arose and her gift for mediating when issues arose between us siblings.

Of course my parents never left her alone in the house, so someone always had to stay back during festivals, family outings, or when visiting relatives. Naturally, the person left behind would feel vexed and resentful.

However, with the dawn of the dreaded illness, her abilities and competencies slowly eroded with her constant proclamation that “this is unfair!” Why her? Hasn’t she suffered enough? There was no equity, no justice, and no fairness! Her whole world had collapsed, her confidence had shattered, her exuberance had faded away and every negative attitude seemed to saturate her mind. It took serious cajolery, constructive persuasion and psychological endeavours to convince her that there was hope that she

must not give up, that she must fight it and that we were all there for her support, comfort and security.

The other psychological impact was when others made fun of her or uttered traumatizing comments about her disability. As siblings, obviously the “blood is thicker than water” emotion will rear its head and the consequences can be damaging.

#### **8.4.3. The Physical Stress**

My sister was very particular about outsiders carrying her. As I grew older, I naturally assumed the role of carrying her whenever she was going out (which were rare occasions). Even before the onset of her illness, I used to help her down the stairs and on to the seat of the car and later help her down again. This did not have much of an effect on me; in fact, I enjoyed when she came out with us in the car, showing her the new developments that had taken place since she last came out and explaining new changes in the roads or traffic flow. However, with the onset of the cancer, her morale had dropped and it seemed to affect her whole being. The radiotherapy and chemotherapy treatments required me to take her very often to Gleneagles Hospital. This entailed carrying her down, helping her into the car, driving her there, assisting her to disembark and placing her on the wheelchair and finally lifting her on to the therapy table. After the session was over the whole process was repeated in reverse to get her back home. This was quite a strain on me physically, as the trips were quite frequent. The whole process drew quite a bit of energy out of me, especially when I had to do it after conducting a lecture or seminar.

#### **8.4.4. The Impact on the Sibling's Own Work**

There was also an effect on my job as a lecturer. Many a time during lectures, I received messages that I should return back immediately after the lecture as my sister had to be rushed to the hospital. Other times, someone had to be with her always so when I was not lecturing, I was on duty with her. This affected my preparations for lectures, as well as other work-related functions, as performing them at the hospital was not convenient. Thoughts of her plight, seeing her health deteriorating and uncertainty over the whole affair played a crucial role in upsetting my mind and affecting my work.

#### **8.5. THE OTHER STORIES**

This section deals with the stories of the various respondents who voluntarily related their life experiences as caregiving siblings. The actual names have been omitted for confidentiality purposes and simple references based on the letters of the alphabet have been used to denote the person for whom the respondent is undertaking, or had undertaken, a caregiving responsibility. While the respondents' stories are presented in verbatim form to the greatest extent possible, corrections have been made to spelling and grammar, and connecting words have been inserted to make them easier to read. Care has been taken to ensure that these corrections have not altered or influenced the content of the stories. The stories commence with Ms. B and C both having a common caregiving sibling, followed by the stories of Mr. D, Mr. E, Mr. F, Mr. G, Mr. H, Ms. I, Ms. J, Ms. K, Mr. L, Mr. M, Ms. N, Ms. P, Ms. Q, Ms. R, Ms. S, and Ms. T. The chapter closes with a conclusion.

### **8.5.1. THE STORY OF MS. B AND C AS RELATED BY THEIR SISTER**

My family comprised of my dad (who was an administrator in a government department, my mum (who was a Tamil school teacher before becoming a housewife) and we three kids. My mum passed away 11 years ago and my dad six years ago. Ever since, I have taken full charge of my sisters' . . . care.

I am currently working at a local private college as a lecturer and also teach part time evening and weekend classes . . . to ensure financial security for all three of us. We live together in our family home in PJ [Petaling Jaya].

Miss B, aged 42, was born totally normal. When she was a few months [old] she had a high fever and fits. She was rushed to Assunta Hospital by our parents. The doctors tried to bring her fever down but it took time. The fever affected her brain and she became speech retarded. She has the vocabulary of a three year old. She understands everything. She talks limited words. She needs help for her toilet needs. She can eat her own food but needs help to bathe and change clothes. She is conscious of hygiene and tidiness as she insists on bathing and changing clothes twice a day. She switches off lights and fan switches if it's not used. She keeps things back in order if it's untidy [such as] newspaper, clothes etc.

Miss C, aged 32, was born normal but with jaundice and had to be in the incubator for 30 days. She was a normal child but found to have a very mild hearing loss in both ears in secondary school, about 25% in both ears. She attended normal school and was a good student. In Form 3, there was a problem: she was victimized by school bullies and

developed fear and anxiety to go to school and was diagnosed with (functional) schizophrenia at the University Hospital. She had to be on lifelong medication (2 – 3 tablets taken once daily). She completed Form 5, did a computer certification and decided she wanted to work. She has good memory and does her work efficiently. She was working as a nurse cum clerk in one of the clinics near our home. She stopped working as she had a relapse due to bullying at work. It took us 1-2 months to get her back to her normal health again.

#### **8.5.2. THE STORY OF MR. D AS RELATED BY HIS BROTHER**

Mr. D was born on 18 October 1988. His father worked as a construction supervisor and his mother was a housewife. He was the second child in a family of six (including the parents). He had a happy childhood, mingling and playing with his siblings, neighbours, friends and relatives.

When he was 7 years old, his parents . . . noticed that he didn't walk straight and normally like others. The parents and relatives . . . thought that was his normal habit. As such, they had advised him to walk straight like others. However, as years passed by, he couldn't walk straight and normal. His parents also . . . noted that he needed support from others even to cross the roads, and that he had started to walk very slowly when he was nine years old. Even others (i.e., friends, neighbours and relatives) had informed my parents that they saw him falling down . . . if he stood for a few minutes. Then, he was brought to Hospital Besar Kuala Lumpur [the General Hospital] to investigate his problem through a medical check-up. The doctor had informed us that Mr. D was

suffering from Friedreich's ataxia, restrictive lung disease and kyphoscoliosis. Doctors had referred his case to Institut Pediatrik [the Pediatric Institute] of Hospital Kuala Lumpur and advised the parents to bring Mr. D for regular check-ups on his disease. The parents had brought him for regular check-ups as advised by the doctors. At this stage, he was attending . . . primary school until he was 12 years old. Subsequently, he attended...secondary school.

One day, at the school, teachers had complained that he had fallen down a few times and he faced difficulties in getting up. Also, they mentioned that Mr. D . . . couldn't move for a few minutes without support from others. This . . . happened when he was 13 years old. His parents . . . brought him immediately to hospital to investigate the matter. The doctors . . . informed them that he was diagnosed with insulin-dependent diabetes mellitus (IDDM) and this had made him wheelchair bound and totally dependent on his parents for his daily activities. This made it difficult for him to get to school. His father had arranged a school van for . . . transporting him to [and from] school. Throughout the years as his disease progressed, the scoliosis worsened, affecting his breathing and sleeping. By now he was 15 years old. For consultation with doctors . . . his medical appointments were up to at least 2-3 days in a week. His parents . . . negotiated with the teachers and the headmaster to allow him to sit the public examination (Penilaian Menengah Rendah, PMR) that year without attending classes since the medical appointments clashed with his classes. The headmaster and teachers . . . agreed on this. After his PMR examination, he didn't go to school due to transportation problems, as his father did not own a car and he was admitted to hospital frequently.

Since then, he was taken care of at home and given some physiotherapy exercises according to the doctors' advice. His father...faced difficulties in caring for this child as his income was insufficient to cover household expenses, children's education, his own medical expenses (our father also suffered from IDDM since he was 26 years old), high blood pressure and skin problems.

Although he was a disabled person, it did not stop him learning...basic computer skills. In 2007, I bought a small desktop to help him learn necessary computer skills using the excess education scholarship funds which had been provided to me. With strong effort...Mr. D...managed to become computer literate in MS Word, MS Excel and MS PowerPoint. Accepting his fate, he had continued with life in this condition watching others progressing with their lives.

In 2009, I . . . graduated and secured a job in one of the Big Four [accounting firms] as an Audit Associate. The financial position of my family . . . improved slightly and I started to support Mr. D . . . financially.

Fate handed him a further blow in 2011 when he was paralyzed for several months. After suffering for several months he . . . returned to the Lord on 25th November 2011.



### **8.5.3. THE STORY OF MR. E AS RELATED BY HIS BROTHER**

On 5-8-2006, Mr. E met with a motor accident while on the way to work (plastic factory, production line), and hurt his left leg (the bone had come out from where the skin had cracked). He was admitted to a . . . government hospital for 49 days. All the payments were borne by my mom from EPF [the Employees Provident Fund, an employee/employer funded retirement scheme] withdrawals of around a few hundred thousand ringgit. He was able to claim accident insurance. SOCSO [the social security authority] only paid compensation of RM4.59 per day, which is still under appeal, and made a one-off payment of RM200 plus. Now he is using a crutch to walk. His brother fetches him...to work. I already asked for help from the Ministry of Welfare . . . last year but until now there is still no news.

...[A]t the government hospital, it was established that the left leg's bone had cracked. The doctor said he could not help . . . and asked him to go back home. After that I took him to Dr. Chin, who did a few . . . operations to remove the remains of the cracked bone inside his left leg. This resulted in . . . wound infections and further medical expenses ensued. After the operations, he started training to walk using a crutch.

After the operations we found another Guan Yin Ting Clinic which is some sort of welfare centre where they specialise in cleaning diabetes patients' wounds. After that the wound healed.

The doctor said there was another way to help the bone grow back but we would need about RM 10,000 [if the procedure was performed at a government hospital], otherwise RM50,000 plus if performed at a private hospital. We are still asking help from other welfare groups and the government for support to raise this fee, as it is too expensive considering that we already used RM100,000 of our savings for the earlier treatments.

#### **8.5.4. THE STORY OF MR. F AS RELATED BY HIS SISTER**

Mr. F was born on 15/11/1972. A cheerful baby, he was active, exuberant and high spirited. Unfortunately at age one he was struck with high malarial fever. Hospitalisation, medication, traditional treatment and all other attempts to cure him failed and he remained a limp body with only facial expressions of emotion. He had lost all feelings in his limbs, which later became deformed. He is immobile, and has to be fed, clothed, cleaned and bathed. Although he subsequently did not suffer from any major medical problems later except for a bout of dengue fever when he was 35, his condition did not improve and he needed constant care. This was provided lovingly by his parents and siblings but with the demise of the father and years of hard laborious work having taken a toll on his mother's health, the ardent [arduous?] task of caring for him fell on his sister.

#### **8.5.5. THE STORY OF MR. G AS RELATED BY HIS BROTHER**

Mr. G was born on 26 June 1953. His father worked as a teacher in Jelebu, Seremban and his mother was a housewife. He was the third child in a family of eleven. He

attended the Sekolah Menengah Anglo Chinese School in Seremban, Negeri Sembilan from 1960 to 1967 and then proceeded to Form One at the same school.

A year back he had been apparently diagnosed with gastric disorders and has been on medication for a couple of years until the day when he started vomiting and having swales [sp. swelling] on his hands and legs. Two to three months thereafter he could hardly walk and that's when it was confirmed that he had lost both his kidneys.

He had been in and out of the Klang General Hospital since then. He was put into many rounds of dialysis treatment to clean his kidneys. He is now half his normal size. Doctors confirm now that he needs to go to a dialysis centre thrice a week to do his dialysis. He has since been going for dialysis without fail. It is actually a whole day affair for three days in a week whereby he needs to be in the machine for close to five hours in a row.

Through the months although weak and fragile, he has to take a commuter [train] to the dialysis centre. It is a long journey from Subang to Klang and he has to take a bus from Subang Jaya to the commuter [train] station and thereafter return from Klang back to Subang Jaya. Accepting his fate, he continued with life in this condition watching others progressing with their lives knowing that his had reached a plateau.

#### **8.5.6. THE STORY OF MR. H AS RELATED BY HIS SISTER**

Mr H was born on 27 August 1940. A teacher, he was very active in sports and was the secretary of the Referees' Board and subsequently rose to become the treasurer of the Football Association of Selangor (FAS).

It was not long after he had taken optional retirement that he discovered that he was suffering from Parkinson's disease. It was a doctor friend who noticed that he walked without swinging his left arm and advised him to see a specialist. He had seen two specialists who had confirmed that he was indeed suffering from Parkinson's disease.

Initially he received complaints from bankers that his signatures on the FAS cheques were becoming illegible and he felt compelled to resign from his position at the association.

Considering Mr. H had led such an active and outgoing lifestyle in the past, Parkinson's disease was really dreadful for him since his movements were significantly restricted. However, he has always remained positive and continues to venture out when he has taken his medication and is able to walk slowly, although not as before. He has had his share of sweet and bitter experiences with members of the general public but has always maintained his dignity and never felt ashamed of his condition.

He laments “I have encountered many types of people; some were very helpful and nice . . . but others have ignored my plea for help or even laughed at my wobbling body movements.”

#### **8.5.7. THE STORY OF MS. I AS RELATED BY HER BROTHER**

Ms. I was born on 2nd October 1972. She was a twin and the fifth child in a family of nine. The second twin, is a male. Ms. I was a shy girl who didn't take part in any of her school activities. The only thing she does is to be the eye and mouth for her father. Her father worked as a fitter with Keretapi Tanah Melayu [the national railroad] and her mother worked at nearby sawmill which offered miserable daily wages. Her ordeal came when she was 10 years old, when ...she was studying in Standard 4.

One day, her mother went to work very early in the morning as usual leaving the others to go to school. Ms. I was not well and told her father that she was having fever. However, her father insisted that she go to school. She went to school but unfortunately fell down half way through. She got up and continued to school and returned home after school. That was the last day she attended school in her life. Her mother came back home late evening and found out that she had a high fever and took her to Gemas Hospital. As they could not help, she was rushed . . . to a bigger hospital at Segamat. She stayed there for a month and a half. She was fine until the last few days before being discharged when her hands and legs started shaking. Her mother was told that it was normal and she needed to take . . . healthy food.

Upon return from Segamat hospital, she was very weak. Though she could walk she preferred to lie down. Her parents gave various traditional healthy foods but not a single change could be seen. As both were earning only enough for survival, the parents were not able to buy her Chinese medicine which may have helped her come out of this ordeal. Gradually she found it difficult to move her legs and eat by herself. Her sisters were a great help for attending to her daily needs. It took hours to feed her but patience served to uplift their morale, because my mother and sisters . . . never complained about . . . this task.

She was taken to Seremban hospital and stayed there for a month and the doctors said she had high fever and it had affected her brain. She was taken to University Hospital in Kuala Lumpur where she went through a lot of scanning and medication. At one point doctors told her parents that they needed to take “water” from her backbone. As both parents were not highly educated and not aware of anything except to see their child get well they agreed to it. A day after that procedure was done, she lost her speech and ability to walk. And the worst part is she could not see clearly. When my mother asked the doctors, she was told . . . that she needs to take more medicine and be given energy food.

Days went by, months and years. She started losing weight, and her sense of hearing and sight too. She was bedridden and never came out of it. It was a big struggle for all our family members who took care of her, especially her mother who spent 25 years with her without seeing the world and things around her. The day came when she had difficulty breathing and was taken to Tampin Hospital, the hospital where she was born 35 years earlier. It was 19 September 2007. Doctors did not give her mother any hope

and everyone in the family was prepared for the worst. She passed away peacefully on 20 September 2007.

#### **8.5.8. THE STORY OF MS. J AS RELATED BY HER BROTHER**

Madam J was born a normal bubbly child. When she was about 2½ years old, she had high fever one day. As with any normal child, at moments like this parents would try to pacify the crying child by giving them what they want so this child had asked for F & N [a local brand of] orange drink.

However, as they opened the bottle of gassy drink, the cork flew out in full force and struck the child, apparently hitting a nerve in the head region. Since that day, she has been experiencing unanticipated bouts of fits at any unanticipated time throughout her life. She went to school at age seven but the teachers had a lot of difficulty coping with her when she got her fits. In the end, she had to be taken out of school in Standard Three and cared for by her parents at home. Her mother passed away earlier, but after her father passed away, her brother and sister-in-law have been taking care of her

#### **8.5.9. THE STORY OF MS. K AS RELATED BY HER BROTHER**

Madam K was born on 7 December 1958. Her father worked as an estate conductor in a rubber plantation. Her mother was a housewife. The tenth child in a family of eighteen, she was a sprightly child. She attended the St. Anne's Convent in Kulim and completed her MCE[Malaysian Certificate of Education, the equivalent of O-levels or the current Sijil Pelajaran Malaysia] in 1978. After her examinations she was forced to stay at home

to take care of her parents and younger brothers. Her three elder sisters were in England working and another sister was married and staying in Kuala Lumpur. For years she was just doing household activities. Day by day she developed a kind of depression and frustration. Initially she would just breakdown and cry but this was not taken seriously. As Indians, we started to seek the help of mediums but saw no improvement. Later her depression got worse and she started to abuse all family members and friends so much so no one wanted to talk to her.

#### **8.5.10. THE STORY OF MR. L AS RELATED BY HIS SISTER**

Mr. L was born on 26 June 1957. His father worked as an auditor in the Federal Audit Department and his mother was a government school English teacher. He is the eldest son in the family followed by a sister who is three years younger than him. He was a bright student in his school days and at the same time was equally active in terms of co-curricular activities especially football and badminton.

Upon completing his Form 6, he was offered a place at University Malaya to do his B.Sc. (Hons) in Mathematics and he continued with his Masters. He obtained first class honours for his bachelor's degree. Upon completing his Masters, the University offered him a scholarship to Pennsylvania State University to do his PhD. He was also tutoring as well at the same university. He didn't encounter any problem until his last semester when he just came back to Kuala Lumpur all of a sudden. The Dean of the University gave him a letter stating he was unable to study or even tutor and allowed him to



continue with his studies once he had completely recovered. He didn't return to USA after that.

When he got back, we took him to a psychiatric doctor and that's when the doctor said that he had schizophrenia (a type of a psychiatric disorder) because of too much strain on his brain and that he was unable to continue with his studies. He underwent treatment and was and still is under medication. At one point, he was already willing to accept the fact about his position whereby he was unable to complete his studies and had to be under medication. After that, with the help of his father, he got a job in the Customs Department as Superintendent Officer. Unfortunately that didn't last long: he was unable to cope with the work pressure and responsibility and so he gave 24 hours' notice and resigned after serving the government for a year to a year and a half. Since then he has been at home and I am looking after him and bearing all his expenses.

#### **8.5.11. THE STORY OF MR. M AS RELATED BY HIS BROTHER**

Mr. M was born on 7 March 1966. He is the eldest among the three children of Mr. & Mrs. S. Mr. M was born with a deformity on both his hands. Besides that, he was born with a bent right leg. His right leg started to bend even more as he grew older. The exact cause of his deformity is not known. It was a tough pill to swallow for both Mr. & Mrs. S as Mr. M was their first child. They were very depressed as most of the their time is spent on thinking about how to bring up this child so that he'll be able to do chores and activities like anyone else. Just as expected, Mr. M had to go through a lot of pain and challenges in his life.

Mr. & Mrs. S did not want to send their son to a special school as they wanted their son to have a normal education just like anyone else. Although they managed to get him into a normal primary school after going through a lot of hassle, little did they know that their son was going to face a lot of obstacles ahead. He was constantly bullied in school. Other students would make fun of his deformity and most of the time just did not bother to be friends with him as he was much different. Mr. M would come home crying to his parents almost every day. But that did not stop Mr. M from being one of the top students in school as he always took into heart the words of wisdom from his parents.

Mr. & Mrs. S were also blessed with two perfectly healthy children. They were the perfect gifts from God as they were born to be the guardians of Mr. M. They were already helping out Mr. M even before reaching primary school. They would button Mr M's shirt, polish his shoes, take him out for a walk and many other activities. As they grew up, they started to take up more responsibilities in taking care of their eldest brother. They would prepare his favourite dish, wash his shoes and clothes, type out his assignments and even helped Mr. M while he was bathing.

#### **8.6.12. THE STORY OF MS. N AS RELATED BY HER BROTHER**

My mother had a premature delivery at around 38 weeks. My sister was a breech footling. Her umbilical cord was wound around her neck. The doctor did a normal delivery and my sister was asphyxiated. She was then diagnosed with cerebral palsy quadriplegia.

### **8.5.13. THE STORY OF MS. P AS RELATED BY HER BROTHER**

When she was 12 years old, she was involved in a car accident on the way . . . back from Malacca to Kuala Lumpur for the celebration of Chinese New Year with her grandmother. Luckily everyone including her mother who was driving, survived. She could...hear her siblings calling her, but she couldn't feel anything else. With the help of others, they called an ambulance, and took her to hospital where she underwent an operation. The doctor said . . . that she broke her back bone and was in a vegetative state.

Every family member, even though they were celebrating Chinese New Year, went to hospital to visit her. She was unconscious after an operation, and the doctor asked her family to be 'ready'. Her father went to pray at every temple... both ...Hindu and Chinese for his daughter, while her mother ...never left the hospital during the week she was in a coma.

A week after that she woke. That was great news for her parents and relatives. But everyone was so afraid to tell her she can never walk anymore. She believed that she was just temporarily disabled and not forever. She...was...so positive and accepted all medical treatment because she believed that she could recover if she listened to the nurses and doctors, because she was just a 12 year old girl. After a month, her mother tried to ask her daughter...if she could never walk again, what would she do? The doctors arranged psychological counselling for her. Trying to let her accept her fate.

After three months, she returned home. She was trained...to use the wheelchair, but she couldn't because she did not have enough energy to push the wheel. She...decided to continue her studies at secondary school. She was so weak after the operations. She couldn't go to school on rainy days, so she missed many classes in a year. However, she worked hard and did revision and practice questions at home when she was absent from school.

In the SPM exam she got 3As which is considered a good result for her. She continued with her studies at UCSI (Diploma in Business) and she performed well. Due to her disability, her father decided to transfer her studies to MMU in multimedia studies...in line with his plan for her future, to become a website designer. Since she was unable to take care of herself, being employed in an office would be easier than being on the move. Unfortunately, she met some unfriendly classmates who did not want to help her (i.e., feed her and change the pen for her, and even the lecturers were trying to avoid her and some even bullied her verbally. After 6 months, she dropped the course at MMU. However, she continues her career path by taking . . . short . . . programming courses to increase her knowledge of programming.

#### **8.5.14. THE STORY OF MS. Q AS RELATED BY HER SISTER**

Madam Q was a cheerful loving mother with two beautiful daughters. She had lost her husband a few years ago. Her life was devoted fully to caring for her family. Being an active person she was rarely down with sickness and ailments except for the usual fever, coughs and colds.

One fateful morning at dawn, she woke up to get a glass of water. As she was coming down the stairs, she probably slipped or tripped on something, tumbled down and lay unconscious at the foot of the stairs. Luckily, her neighbour dropped in later at about eight o'clock. Not getting any response after knocking on the door, she went to the back and through the back window saw Madam Q lying on the floor. She broke down the back door and rushed to Madam Q, raised her head and saw blood on the floor. However, she was breathing and the neighbour got help and quickly rushed her to the nearest hospital. The doctors diagnosed that she had suffered severe head injuries which had affected most of her faculties. She was alive, but that was all. There was no recognition, no talking, no hearing, and she was a mere vegetable! Her daughters were attending college in another state, therefore, her elder sister had to come over to take care of her. This is her story.

#### **8.5.15. THE STORY OF MS. R AS RELATED BY HER BROTHER**

Ms R is a single woman. Her father was a retired civil servant who passed away two years ago. Her mother is a housewife and still living. She has five siblings who . . . are all married. She is supported by her brothers in terms of giving her a monthly allowance and taking care of her other needs such as medical. She does not suffer any critical illness except that she is a gout patient. She has a Form Three education and worked for a few years in her early twenties as a factory operator. However, she was a slow learner and was soon relieved of her duties and forced to resign. She just could not hold down any jobs, so we felt it was best that she just stayed at home and helped out with the children etc.

#### **8.5.16. THE STORY OF MS. S AS RELATED BY HER SISTER**

Madam S was born on 27 January 1949. Her father worked as a manager on a rubber estate and her mother was a housewife. She was the second child in a family of ten (including the parents), and had a happy childhood. She attended the Holy Infant Jesus Convent School in Johor Bahru from 1956 to 1966. After completing her Form 5, she had to work as a lab assistant in the Convent school because by this time the father had left the family and the mother was just doing odd jobs to make ends meet

At the age of 19, she found out that a teacher she liked was going to marry another woman and this came as a big shock to her. Something snapped and she went into a depression. My mother tried all the ‘other’ means of curing her but it was all in vain. Then we took her to the Tampoi Hospital, where they ran many tests and put her on anti-depressants.

Through the years, we took her in and out of the mental hospital and she was always under the care of my mother. When my mother passed away in 2003, only five siblings agreed to help by contributing RM200 monthly. By 2006, each one of them had washed their hands of her and I took it upon myself to care for her. Her condition deteriorated through the years.

In 2011, I opted for early retirement on reasons related to my health. Since I was unable to care for her the way I used to, I had no choice but to place her in a home for the mentally ill. With my pension income, I pay for her upkeep in this home and make sure

I visit her as often as I can. I make it a point to bring her to my home once a month where I bathe her and give her a good time.

#### **8.5.17. THE STORY OF MS.T AS RELATED BY HER BROTHER**

She was born in 1965. Her father was a postman and her mother was a housewife. When she was a few months old, she fell sick and was having fever. At that time her mother thought that it was only normal fever. Only after a few months . . . did she recover from her fever. However, only as she was growing up did her mother know she could not speak and . . . hear.

Her parents brought her to the clinic. The doctor confirmed . . . that their daughter could not speak and could not hear. Even with her disability she grew up as a normal kid.

Then her parents moved to Selangor. There she went to a class for the disabled sponsored by the Welfare Department. Her father has been doing oil palm farming so till now, part of the income goes to her.

#### **8.7. CONCLUSION**

The stories are saturated with emotions, feelings and sentiments. Each has its unique storyline, none similar in detail and setting, yet there is a strange relationship, a pervading cohesiveness, a bonding of some sort between them. The notion of love, the

message of care, and the degree of concern permeates through each of the stories, unifying them into a pattern of synonymy. In the next chapter we will analyse the themes that have emerged from the responses received from the caregiving siblings.



## **CHAPTER 9**

### **EMERGING THEMES**

#### **9.1. INTRODUCTION**

This chapter discusses the results of the NVivo coding analysis conducted on the transcripts, evaluates the emerging themes that have been identified and views them through the theoretical lens of Schumacher's philosophy. The chapter is organised as follows:

Section 10.2 presents Schumacher's first principle followed by the second, third, fourth, fifth and sixth principles in Section 10.3 to 10.7. Section 10.8 looks at the influence of religion on the caregiving role and finally Section 10.9 concludes the chapter.

The themes emerging from the data, together with their personification when interpreted using Schumacher's philosophical principles, are presented next.

#### **9.2. SCHUMACHER'S FIRST PRINCIPLE**

Schumacher states that the total reliance on nature's assets and capital is foolish because of its depleting attribute. Similarly, the state should attempt to assist these caregivers in every way possible because if they abdicate their role and government has to assume the responsibility of caring for all these persons with disabilities, the implications (both

financial and non-financial) will be tremendous. One way of providing this assistance would be through the provision of tax relief for the sibling caregivers.

Peering through the lens of Schumacher, we exit from the macro platform and step on to the micro (i.e., small is beautiful) one. Similarly, the findings reveal that the function of caregiving has affected the lives of the caregiver in minute ways: with a touch of their compassionate side, placing a harness on their boiling tempers, nurturing a cajoling nature, and generally providing them with a sense of gratitude for every small goodness that comes their way.

This is discussed in the light of the emerging themes below.

### **9.2.1. The Difficult Moments in Caregiving**

An obvious response from many siblings taking care of a person with a disability was the attitude of the other members of society towards them; a look of repulsion, curious glances seemingly saturated with disgust, passing comments which, although not audible, were so obviously in reference to the person with a disability. To be fair, of course, there are those with genuine care, sincere compassion and unpretentious sympathy.

#### *9.2.1.1. Attitude of Society at Large*

As Ms. N's brother reports: "when we go shopping, we . . . receive stares from strangers when they see my sister all strapped up in her wheelchair." The sister of Ms. B and C remarks that she had to "adapt and adjust [to their] funny looks." She feels disappointed

with parts of Malaysian society, and feels that “the Westerners are more open minded and caring.” She recalls an incident at the Thaipusam festival one day when Ms. B “was feeling dizzy [and] fainted . . . the Malaysians looked and stared while three American men and two ladies rushed towards us, helped to lift my sister and carried her to the Red Cross shed.” The sister of Mr. H laments, “there is also the social stigma attachment to the disease, as people tend to stare at him at public places.”

#### *9.2.1.2. Feelings of the Person with a Disability*

For the person with a disability it is also very hurting when members of the public pass snide remarks, nasty comments and make spiteful statements. Mr. L’s sister recalls that when he first returned from the USA, “he turned a little aggressive and so was admitted in the hospital for treatment in order to calm him down. However, because of this even . . . when he goes to the nearby shop, people . . . think he is of unsound mind and make fun [of him].” She continues: “they just fail to realise how hurting that can be for a person.” Similar emotions are expressed by the brother of Mr. M when he says “sometimes people make fun of him . . . he used to cry a lot. These were really difficult moments.”

#### *9.2.1.3. Communicational Block*

Comprehending persons with disabilities can also be an arduous task when they are unable to communicate properly, or their speech is highly inhibited. Mr. F’s sister relates that he is unable to “express himself so like even when he passes motion during the day . . . he sometimes twitches his toes in a way but other times it’s through the smell that we can know about it. Otherwise he shouts sometimes if he is unable to turn

himself, or needs a drink etc. but it is quite difficult at times to understand what is it that he really wants.” Ms. N’s brother agrees that “it’s not easy to take care of a person who is bed-ridden and more so, unable to communicate. We had to try [to] make sense of her utterances and sounds.” Similarly, the brother of Ms. J remarks that “you don’t know when it’s coming” [referring to her attack of the fits]. There are “no tell-tale signs etc . . . but when it’s on you must not panic, [you need to] stay calm and make sure nothing is around which she can hurt herself with because they [the person suffering the fits] don’t know what they are doing.”

#### *9.2.1.4. Time Factor*

Having a person with a disability in one’s care is at times a “24/7 job”, where round the clock vigilance is needed. Even attending to personal matters requires the presence of a replacement caregiver before the person with a disability can be left. As the sister of Mr. F laments: “he is only used to me and a few close family members, so I cannot leave him with anyone [else]. That stifles my movement away from home . . . cannot go for weddings, birthday parties, and engagements” she says, recounting the numerous joyful occasions that she had to miss. As the brother of Ms. N says: “in the course of [the last] 20 years, we had to bathe her, take care of her hygiene, her bowels, and all aspects of herself. We have become more or less inured by this constant workload. We are not able to travel overseas as a family for we do not want to leave my sister behind.”

#### *9.2.1.5. Physical Strain*

The physical strain factor is highlighted by the sister of Mr. H, who describes how difficult it is to “lift . . . him up from the bed or the chair.” Ms. J’s brother also remarks

that “bringing her out is quite a chore [because] controlling her during the attack[of fits] is hard, especially when in public. People just stare . . . no one helps.” This is echoed by the sister of Ms. Q:

*Every day I carried her to [the] bathroom to bathe her and for this I faced some difficulties; sometimes she is very weak, at this time I struggled a lot. Also cleaning her and turning her is difficult as she is quite big and heavy.*

#### 9.2.1.6. Mental Strain

Psychological support is also important in providing the will to continue living, especially when the disability is not from birth. The brother of Ms. P cries: “the most unforgettable memories would be [her] younger days when she still can’t accept herself as disabled, and other siblings [were] not really giving support to her. That period [was] her most depressed time and even she did tell me she thought to suicide.” This works both ways: at times the sibling is the one who needs the strength to withstand the strain of caregiving, as in the case of Ms. K (who suffers from mental depression), whose brother complains: “according to her she is normal,[and it’s] the other family members [who] are not normal. Therefore, she refuses to take medication . . . [also the] use of abusive and hurting words to family members was unbearable.”

However, whatever the strain, the pain, the anguish, none of the sibling caregivers expressed any regret, disdain for, or repulsion of, their responsibility. They took it in stride as an opportunity to help another and at times with a sense of gratitude, as Ms. S’s sister states: “it was very difficult to know that no one wanted to care for her especially when my mother died. I know how much she had done for her siblings when we were young. She being the second in the family had to carry many burdens as my mother was

the only breadwinner and she decided to work right after [fifth form examinations] to help the family financially.”

It is obvious that a great strain looms over the heads of these sibling caregivers. As Schumacher states, the total reliance on nature’s assets and capital is foolish because of its depleting attribute. Similarly, the state should attempt to assist these caregivers in every way possible because if they abdicate their role and government has to assume the responsibility of caring for all these persons with disabilities, the implications (both financial and non-financial) will be tremendous. One way of providing this assistance would be through the provision of tax relief for the sibling caregivers.

Next we discuss on the theme of the influence on the sibling caregiver’s life

### **9.2.2. Influence On The Sibling Caregiver’s Life**

Undertaking the caregiver function has a colossal impact on the caregiver’s life. Most of the siblings noted a positive turn in their lives, in terms of both the transformation of their character and in their outlook on life.

#### *9.2.2.1. Impact on Character*

The transcripts are amply littered with admissions of changes in personality and disposition with “I have become [a] more caring and understanding person”, and “it teaches you to be calmer [and you learn to be] . . . patient ...” says the brother of Ms. J, who suffers from fits “[because] . . . when she is having her fits, if you get angry . . . it

makes matters worse.” Another notes: “my character also changed; my perception about the world also had changed. I [have] come to [a] point that anything could happen to anybody at any time.” Yet another proclaims that caregiving has made her “more compassionate, kind and patient” and “made me a better person with a strong will and character.” The sister of Ms. B and C says that she “had to learn to care for them as my parents did” and therefore had to mould her character to become a strong and valiant person because she felt her sisters were “very sensitive” and had to be “protected from the harsh realities of life.” She equates it to “being a sword; to destroy negative effects and a shield to protect them from the brutal realities of the world.”

#### 9.2.2.2. *Outlook on Life*

The comments started with “I appreciate more what I have in life and [do] not grumble about what’s lacking because comparatively he [the person with a disability] doesn’t even have what I have”, and “it has taught me to appreciate what I have and be grateful.” The words then move to reflections such as “it makes you look at life in a different way and to be more appreciative of what it has to offer”, and “we always take life for granted until we see others suffering . . . then we start to realize that we are the lucky ones.” One respondent’s comment admonishes not to “lose sight of the fact that I too can be crippled or lose the use of any of my faculties in future.” An evolutionary change was also expressed by the sister of Mr. F when she states:

*I was only 10 plus then, literally a child myself but I could see the pain in my parents’ faces, worry of how to raise him and that affected me of course. So slowly I got accustomed to doing things for him; cleaning, feeding etc.*

There was, however, some expression of bottled-up anger and frustration: “I was thinking that why God has to punish my sister so hard. She does not deserve to be like

this”, but tempered with the wish “I was hoping that God will make her well one day.” Others literally suffered: “it’s a torture staying with a person with a mental depression. Thus there is no peace in the family. I was really stressed up and what’s happening to her. Is she going mad? And how to make her understand that she needs treatment by a psychiatrist.”

A majestic finish is furnished by Ms. S’s sister: “I see the world in a different light and thank God every day for giving me this life”, and by Ms. N’s brother, who adds “my sister is bed-ridden since she was born. I have learned to be more humble, to take life with a pinch of salt. Not to take things too seriously and always to be grateful for all the little things that we have.”

The third theme merging in line with this principle is the issue of placing the persons with disabilities at a home or institution which is discussed next.

### **9.2.3. Placement In A Home Or Institution**

The topic of placing the disabled person in a home or institution is generally dismissed by almost all the siblings. It is taboo! Starting with chants of “he is our child, God wants us to take care of him that’s why he was placed here in our family . . . why pass him to others to take care of”, through to “he is born in the same womb of my mother. We never had such intention to leave him in an institution or home”, and “I personally believe that nobody can take care of him as [well] as my parents”, the sentiments were pretty much unanimous. They culminated with: “she is my lovely sister and [I] never



think [of] sending her to [a] home. I [have] decided whatever it is, we will take care [of her] until her last day.”

The main worry about placement in a home or institution is whether the level of care will be the same. As the brother of Mr. D explains: “my parents did not want to place him [in a home] as they doubt whether [these] homes can take care [of his brother as well as his] . . . parents. This is because the welfare homes have huge numbers of disabled persons to take care [of].” This was in spite of Mr. D having “requested personally to my parents to place him at any welfare homes so that he wouldn’t become burden to our family.” Also, the brother of Ms. P worries that “the workers will bully her. Anyhow she can’t even go [to the] toilet by [her] own, so we don’t think it’s suitable to place her there.” The sister of Mr. L remarks that “he is harmless and not a nuisance at all in any way.”

However, in some cases, there was no alternative but to place the person with a disability in a home. As the brother of Ms. K explained, although the initial intention upon discovering her mental depression was to place her in an institution, “all of us did not have the heart to do so, so all took turns to keep her with them . . . it’s a large family so [there were] lots of families for her to stay with.” However, with the advent of time “we [were] all also old already and our kids [were] all working so [we were] forced to send her to a home.” The same sentiment is echoed by the sister of Ms. S when she says: “my mother always felt that she would not be cared for well in a home and would be better off at home with us. Cost was also a factor then, as we were not well off. My mother was the only breadwinner in our family.” She continues: “[however] in . . . 2011, I opted for early retirement on reasons related to my health. Since I was unable to care

for her the way I used to, I had no choice but to place her in a home for the mentally ill. With my pension income, I pay for her upkeep in this home and make sure I visit her as often as I can. I make it a point to bring her to my home once a month where I bathe her . . . and give her a good time.”

Some exhibit sheer grit in ensuring that their beloved disabled sibling is well cared for by themselves, irrespective of the consequences. The sister of Ms. B and C relates how she has remained single due to “the stigma, or should I say the mentality. of the Indian community, whether proposed or love . . . [at the] end of the day it was an issue with the families as they insisted [that] my sister ...be placed in a home or orphanage if I chose to get married.” However, she brushed them aside and says “my choice [is] my sisters. I pray God blesses me with good health and good wealth so I am able to care for them till their last days.” This is indeed a commendable sacrifice.

The state has to realise that placing all persons with disabilities in institutions will have a heavy impact on their annual budgets; the impact would be compounded by a range of unanticipated problems. Obviously, the rendering of assistance to caregivers would be a much better solution than establishing and administering state-run homes and institutions. This has always been the advice of Schumacher: by focusing its attention on the layman, government will ultimately benefit by leaps and bounds.

The rendering of assistance to caregivers would also be in line with the Malaysian government’s objective of nurturing a caring society. It would complement its efforts to enhance the quality of life of the rakyat (citizens of Malaysia), as detailed in the 2011

Budget. While the Budget introduced tax relief for caregivers, the relief was restricted to children caring for their parents.

### **9.3. SCHUMACHER'S SECOND PRINCIPLE**

Schumacher's opines that innovations in science and technology should be re-orientated so they can be used by everyone with minimal destructive and disruptive effects on mankind and its relevance to this study is that bestowing tax reliefs on persons with disabilities serves no purpose if they have no income to absorb the relief. Instead, it should be granted to those supporting the persons with disabilities so that firstly, it can be utilised productively and secondly, provides a sense of satisfaction and recognition for the caregiver. As the saying goes, "great pines from little acorns grow". Schumacher emphasises too, in theory, that when the little man on the street is satisfied, it leads to a perseverant and involved attitude culminating in immense prosperity for the nation as a whole.

As emphasised always by Schumacher, the direction of the nation's growth lies in the hands of the citizens, whose happiness and contentment will serve tremendously towards steering the development of the country to a higher plain.

In the light of this principle, the theme of the present state of welfare in Malaysia is discussed next.

### 9.3.1. Current State of Welfare in Malaysia

In spite of major government programmes to assist the disabled, the innovative steps taken to alleviate their suffering, the introduction of various facilities to aid their movement, the help provided to engage them in employment, and involve them in recreation and development activities, the respondents' reactions to these initiatives was lukewarm at best. There was half-hearted acknowledgement that "basic facilities are given in some public places" and "medical-wise [it is] cheaper in public hospital." The sister of Ms. B and C remarks, "it seems like [they do provide] basic amenities . . . e.g., LRT seats, parking bays for OKU [etc.]", but she notes that "even that is abused by our not so socially aware community . . . [because] . . . we see normal people using them and the disabled are still disabled and suffering." The negative views are abundant, as detailed below.

#### 9.3.1.1. *Nay! It is Bad*

It starts with a simple side stepping by the sister of Mr. L: "I don't know, I mean we got nothing in my brother's case . . . even the free treatment in government hospitals is only for my parents not for the kids you know." Then a polite refute from the brother of Mr. E: "Malaysia OKU facilities [are] very limited. Maybe more in KL city but Johor here not really can see it." It continues on in a courteous tone, with Ms. K's brother remarking: "don't think much done for the depression patient – except give medication or sending to rehabilitation centre. Nothing constructive towards helping them lead a normal life again." It cascades to "calling a spade, a spade", with the brother of Mr. M expressing his opinion that "to be honest, our government has not done much. Not much funds are allocated to aid the disabled. Even if there were funds allocated, to get it is a

very big hassle, a lot of paper work has to be done and by the time we get the funds, we had to go through financial constraints.” It ends with the blatant retort, “my mother and I didn’t see anything . . . we had to carry our own burden”, by the sister of Ms. S. The culmination is a direct sarcastic rebuke from the brother of Ms. I:

*Really? I guess you must be talking to someone connected to a political party. I am not involved in any and I nor my family did not get any aid for the past 25 years. There were many NGOs around but none of them gave a helping hand to ease our burden. Maybe it is only applicable for urban disabled people and not for [those from the] outskirts. I rarely heard of any disabled [person] given support at my neighbourhood. If yes, they must have known someone in politics.*

#### 9.3.1.2. Tales of Woe

The sister of Mr. F relates about the run-around they had to endure in her brother’s case:

*We registered him with the welfare department and received RM 300 a month which was used for his pampers and special milk powder etc. However, he never got an identity card (IC)(identity card for Malaysian citizens), the department said the “disability card” was enough. So my father was collecting the money on his behalf. Upon his demise, they refused to give us the money and wanted to see his IC. But when we wanted to register him at the registration department they said an IC has already been issued in his name but we said that’s impossible since the birth certificate is with us. We had to submit copies of the ICs of all his siblings and that of my mother, submit numerous forms and still no IC for my brother. After a lot of travelling between welfare, registration departments and the homes of politicians, finally they were willing to give the RM 300 to my mother but we still don’t have an IC for my brother.*

The brother of Mr. D narrates his story:

*Earlier, in 2005 when we wanted to register him with social welfare there was such a hassle. My father was just a construction supervisor and at that time I was still taking my Diploma course and my other siblings were still at secondary and primary education level. How would my father’s income would sufficient for our entire family? My brother (Mr. D) has no source of income . . . how is he to survive? They [Department of Social Welfare] argue with my father: oh! Your income had exceeded the minimum level of RM1,500. You could use your EPF funds also. It seems their argument was not logical at all! Then all their annual allocations are used for what?*

*In this new century, RM1,500 was a small amount to be spent for an entire family. Subsequently, we had written an appeal letter to the relevant ministry. After 3 years (2008) through regular follow-up with the ministry, finally our application (for RM300 monthly allocation) was approved (even that was after a strong recommendation from one of the YB who is (one of the) Deputy Ministers in Prime Minister's Department.*

A parallel saga is voiced by the sister of Ms. B and C: “the government or Welfare Department should assist the caregivers of OKU people. I tried once to apply for financial aid but the Welfare Department said the incentive is only for household income below RM400. I hope, under [the 1] Malaysia [scheme] something good is done for the caregivers of disabled or handicapped people.” She continues: “we help the whole world when there is a tragedy or crisis. Charity starts at home. The government should take care of caregivers and the disabled and handicapped before looking out for others. Additional expense is always a burden.”

The brother of Mr. G recounts:

*In my brother's case he has stopped working. Therefore, public facilities and accessories for helping the disabled at the work place are not applicable to him. He feels weak and feels like he should just sit and wait for the next dialysis. He needs to be told and motivated at all times or else he seemed to be declining in life . . . [he's] very demotivated. Now both my wife and I are working, the kids are busy with their studies so we can't take him out for walks etc. Maybe if there was a full time maid who could take him out of the house, you know, just put him in a wheelchair and push him around in the park or something, he'll feel better. But we can't afford a maid. His expenses itself is causing a serious relook at our monthly budget!*

#### *9.3.1.3. Suggestions Offered*

Ms. J's brother offers “they must help more . . . medicine and treatment should be free. Reduce the waiting time for disabled like her case [person suffering from fits] because too much tension she breaks into fits and it's hard to control.” The sister of Mr. H proposes “providing free transportation for the disabled . . . not just [for the] bus[but

also] . . . including taxis.” When asked about the impact on the driver’s earnings she replied that there “must [be] a system where the [drivers] can claim back from government.” She recommends that the government seriously look at ways of “helping out with the costs associated with caring for them . . . handicapped and very sick people.” She suggests that it “should be in the Budget each year. Perhaps some allowances to help care for these people not only in terms of medical bills but also employing help such as a maid to help care for them. The Budgets always are for the working public . . . what about those who have retired, [and the] sick and disabled? The government should have a conscience and provide some form of assistance in terms of finance as well as providing more amenities catered for the disabled.” The brother of Ms. N concludes the discussion with: “even the personal relief my parents used to get for a disabled child is too little . . . there should be more support given to families with disabled members, both financially and moral support.”

What welfare benefits will be useful is the other emerging theme which discussed below.

### **9.3.2. What Welfare Benefits Will Be Useful**

The list is rattled off by the sister of Ms. B and C: “free medicine and treatment be it outpatient or inpatient, no waiting lines, more incentives for caregivers so that there is lesser abandoned siblings and parents [in the form of] higher pensions, monthly allowances for living [expenses], food and accommodation [and lastly] tax exemption or relief, for each disabled being looked after.” She clearly explains “all caregiving expenses for the disabled should be accounted for as the disabled are also members of

society who are unable to fend for themselves [and if the] government . . . assists the caregivers to care for the needy [then] there won't be that much of welfare cases."

The general reply to the above question revolved around addressing the cost factor, although it was phrased in numerous ways. "We can take care of him, but the medical expenses and transportation costs can come to quite a bit; so I guess it comes down to a monetary benefit", says Mr. D's brother. This is echoed by the sister of Mr. F: "what would be helpful will be monetary help . . . at least we can get good medication to boost his strength, you know maybe he can turn himself can even sit up maybe, make him stronger." The brother of Mr. G reasons it out:

*I guess ultimately it boils down to monetary assistance. Because if you say in term of facilities, then can welfare department ensure someone comes over to take care of him every day? No, right? So we have to manage and for that we need money.*

Similarly, the brother of Mr. M remarks, "with money I would have been able to do an operation to fix his leg or at least [have] given him a good walking equipment aid." Reflectively, Ms. S's sister confesses: "especially now since I've stopped work and don't have a full salary but only a pension, I guess it boils down to money." To ensure transparency, the brother of Ms. J suggests "if they want receipt also can give."

Ms. R's brother wanted "financial assistance for [the] sibling's family's education sponsorship as well as for maintenance cost of unmarried siblings"; although his sister was not a person with a disability, he nevertheless had to support her plus manage the maintenance of his own family.



However, the brother of Ms. K did not yearn for a monetary aid but instead wished for “a good home with good care with qualified doctors and nurses [to take care of his mentally depressed sister].”

The brother of Ms. N admits that “frankly I’m okay even financially”, but he remembers how his “parents suffered financial stress when we were all growing up because the family income was halved when my mother resigned to take care of my sister.” He informs that “some countries actually compensate a breadwinner when the person has to give up their job to be a caregiver.”

#### **9.4. SCHUMACHER’S THIRD PRINCIPLE**

Schumacher always emphasises the greatness of “the small”. Judging from the opinions above and as seen through the lens of Schumacher, one recognises that in spite of our ambitious ideas, strategies and dreams, we should not forget that every human being in this country is a valuable soul who, if constructively evaluated, will present a contribution no matter how small.

In line with Schumacher’s philosophy, the human element is very important. No amount of technological advancement can replace every task, especially the task of caregiving which, aside from the financial cost, the labour and capital expenditure, involves the extension of love, care and attention. Similarly, even though an endowment, rebate or relief may not fully compensate the sacrifices made by the caregiver, it nevertheless indicates some recognition which may help to at least put a smile on his/her face.

One of Schumacher's philosophical thoughts is that progress should be universal, enjoyed by everyone, and be something that permeates through and nourishes every person in society. Therefore, a lack of concern for the sacrifices made and problems faced by siblings of persons with disabilities will retard them in terms of career development, hinder their advancement and curtail their progress in life generally.

The ideal of ensuring that progress should be universal, with benefits reaching everyone, is in line with the Malaysian government's New Economic Model (NEM). The NEM is to be achieved through the Economic Transformation Programme (ETP), which constitutes a key pillar in plans to transform Malaysia into a developed, high-income economy that is both inclusive and sustainable. One of the fundamental objectives of this programme is enhancing the quality of life and the well-being of citizens, which entails efforts to provide assistance to the less fortunate.

This initiates a discussion on the theme of the character of the persons with disabilities as described by the sibling caregivers.

#### **9.4.1. Character Description of the Disabled Person**

This theme served to vividly illustrate Schumacher's principle of "small is beautiful" in terms of the strong characteristics displayed by the persons with disabilities as testified by the caregivers. These are detailed in the discussion below.

#### *9.4.1.1. Loving and Caring*

Phrases of them being “awesome” and “very loving” are echoed by the sister of Ms. B and C, while the brother of Ms. N, sees her as one of his “motivators” as despite her disability, “she always has a cheerful countenance.” The sister of Ms. S describes her as being a “kind and self-motivated individual.”

#### *9.4.1.2. Helpful*

Many acknowledged how useful it was to have them around, extolling their usefulness and how helpful they are. The sibling of Ms. C noted how she “manages her day by keeping an eye on Ms. B” (the other disabled sister), “manages the household and the maid” and even confesses that “she looks after me and her other sister when we are unwell.” The siblings of Ms. R exalt her worthiness, saying “she is of much help in the house . . . by taking care of the house as well as helping out in one of the brothers’ grocery shop.”

#### *9.4.1.3. Self-excelling*

Some commend their ability to acquire new knowledge: as the brother of Mr. D proclaims, “he had learned MS Word, MS Excel and MS PowerPoint by himself by just referring to some manual guidebook . . . [proving] that he wants to be self-dependent and [was]willing to learn.” Ms. P’s brother praises her “fortitude” and how she used to “put all mind into [her] studies.” Ms. K’s brother describes his sister as “a bright person

with good command of English”, and laments that the stifling of this brightness was brought about because her “parents did not allow her to further her studies.” This contributed significantly towards her dejection and downheartedness and “finally she landed up as a mental depression person.”

#### *9.4.1.4. Perseverance*

The urge to be independent is seen from Mr. F’s sister who says: “when young before the illness . . . he was highly excitable wanting to crawl, [wanting to] walk [i.e., he didn’t] want to be carried too much . . . even now I see him trying to turn on his own, amuse himself . . .” Mr. H’s sister also acknowledges that “he is a very strong person.” She continues “he is not one to give up hope easily; he often says that he is able to do things on his own such as bathing as he does not want to burden others.” The sibling of Mr. M notes that “he always [has] an urge to prove to others that he is capable of achieving what a normal person can.”

Sometimes, however, it is not from a lack of independence or a purposely concocted drama that they are not able to help themselves, but rather from a phobia from past experiences. As the brother of Ms. J says: “initially she was very self-motivated . . . she didn’t want anyone doing things for her . . . was independent but once she fell down whilst experiencing a seizure . . . then she lost confidence [to do things on her own] . . . like she needed someone to be around always . . . [she was] scared.”

#### *9.4.1.5. Intellectual Capabilities*

The sister of Mr. F prophesises “who knows he might have turned out to be a good professional”, as does the brother of Ms. N when he proclaims “I believe if she was not disabled, she would excel in her life.” Ms. S’s sister remarks: “I believe she could have had a good life if not for this illness. She would be a very good teacher for I still remember how she patiently taught me.”

However, a tinge of disappointment was evident in the case of Mr. G, whose brother felt that he was “rather pessimistic whenever he falls sick.” He protests that even earlier, whenever he was sick, “he would simply take unpaid leave between 2 to 3 months and expect his mother or his sister to take care of him.”

Another theme arising is the impact of the caregiving function on the work of the sibling.

#### **9.4.2. The Impact on the Caregiver’s Work**

Generally, sibling caregivers can be divided into three categories. First, they may be working people with other members of their family pitching in to take care of the disabled sibling when they are at work. This is the case of the caregivers of Ms. B and C, Mr. D, Mr. E, Mr. G, Ms. I, Mr. L, Mr. M, Ms. N and Ms. P. Alternatively, the person with a disability is placed in a home or an institution, as in the case of the caregivers of Ms. K and Ms. S. The second group consists of those who were working

but had to give up their jobs to care for their disabled sibling, as in the case of the caregivers of Mr. F and Ms. J. The third category comprises of caregivers who are not working, although they may do occasional part-time jobs to supplement their income, as in the case of the caregivers of Mr. H and Ms. Q. The first two categories of caregivers illuminate our understanding of how the caregiving responsibility can affect their work by sharing their stories.

#### *9.4.2.1. Loss of Opportunities*

The sister of Ms. B and C explains that she “had to stick to a low paying job as it’s near my home”, which facilitated a fast return and more frequent visits to ensure everything was under control at home. As a professional, other more lucrative jobs came her way but it was just not feasible to take them as they would have interfered with her caregiving responsibilities. Mr. L’s sister adds: “I was a jack of all trades: an event organiser, news reader, freelance MC etc. . . . purely on a freelance basis [but when] . . . he fell ‘sick’ a lot of lucrative engagements had to be forgone. I still do some events, I mean I need to survive right . . . [however I] . . . lost out on quite a few good ones.” The tale continues at the home of Mr. M, whose brother comments “we had to find a job which is very near to our house [so that] we will reach him anytime in cases of emergency because our parents are old and will not be able to transport him, [plus] we go back [at] lunchtime to check on him and also to spend some time with him.”

The loss of opportunities can also take the form of lost opportunities relating to career advancement in the job itself. As the brother of Ms. G puts it, “performance evaluations are affected [which leads] to restricted promotions.”

#### 9.4.2.2. Transportation

This normally arises where the person with a disability has to be taken for medical appointments and treatments. Mr. D's brother relates how his parents, as they grew older, could not take his brother for check-ups on their own and needed his assistance. Juggling this with his audit work "where the deadline given to us very tight", is a very intricate task which involves the "need to negotiate with my superior to allow me to work . . . after the normal official hours [to make up for lost time]." He remorsefully quips, "sometimes I feel like telling my mom to just call a cab to the house but I feel so guilty to do that." The same sorrowful tale is echoed by the brother of Mr. E: "we all take turns to send brother . . . for medical check. Sometimes need to take unpaid leave to send him . . . but [if] possible [we] make [the] appointment on weekends."

#### 9.4.2.3. Disruption at Work

Most types of work, be they employment or business, require some degree of focus, dedication, and commitment which is very difficult to compromise. The brother of Mr. D also recalls "sometimes I couldn't concentrate, as I might receive call from my parents at [the office] late [at] night . . . reminding me about the date of [an] appointment."

Mr. G's brother illustrates this vividly:

*Sometimes he'll call saying he's weak and [ask whether I] can . . . send him to the hospital. I'm a lecturer . . . how to just cancel classes and work out? Even if no class I can't just leave the college. I'm not a part-timer, and full time staff sometimes [have] admin work [to complete] or meetings[to attend] . . . so [I] can't just up and go. I mean*

*once in a while [it's okay], but always giving the excuse that my brother needs me, then how?*

Lack of understanding by superiors is also experienced by the brother of Mr. M, with his lament that “we quite often can’t attend office functions . . . some bosses are understanding whereas some feel we are not committed to the job, unsociable etc.”

Ms. K’s brother also remarks that “once I come back from work she starts complaining and uses abusive words against my wife and me. So it of course affects your work when you go back to work the next day.”

#### *9.4.2.4. Scheduling Factor*

When the person with a disability needs someone to always be around, time and timing become essential. The sister of Mr. H remarks that although she does not have a full time job, any trips away from home have to be carefully structured because the maid has other duties as well and cannot be with her brother all the time.

The sister of Ms. S is a teacher. She indicates indignantly :

*I had to leave school early to make sure she gets to the hospital for her appointments. When she was admitted to Tanjung Rambutan [a mental hospital], I had to take leave and rush to Ipoh to see the doctor who will interview me during office hours. [I] get annoyed with the school administrators who give me a sick look every time I leave early or take leave. [I] get frustrated for there is no one else to help me even though she has 6 other siblings. It's hard to live with a mentally ill sibling.*



#### *9.4.2.5. Sacrificing the Job*

The act of actually leaving employment for the sole purpose of undertaking the caregiving responsibility is truly commendable, laudable and praiseworthy. However, it is done voluntarily as an act of love as Mr. F's sister says: "I used to work but after my mother got sick I have to be at home to take care of her." The sister of Ms. Q expresses remorsefully that her part-time seamstress job had to be abandoned when she assumed the caregiving function: "of course my children make sure all my needs are met but [there's] nothing like earning your own money."

#### *9.4.2.6. All is Not Bad!*

Despite some of the gloomy scenarios recounted by respondent sibling caregivers, a gleam of light is seen in the words of the brother of Ms. N as he reports "my professional work had improved tremendously as it has taught me to be more patient when dealing with my students."

The third theme emerging are the sacrifices made by the sibling caregiver.

### **9.4.3. Sacrifices Made By the Sibling Caregiver**

"There is a major sacrifice," announces Ms. B and C's sister, "financially, emotionally and psychologically" in affirming that the acceptance of the caregiving responsibility

does involve an element of “loss” and “disadvantage.” Analyses of the views of the respondents reveal the following sacrifices.

#### *9.4.3.1. Attendance at Functions*

The sister of Ms. B and C proclaims, “I hardly have a social life or time for myself, because of the additional time spent caring for them.” Ms. Q’s sister laments that “I [could not] go to temple every day [and] had to cancel many important functions.” A similar remark is made by Mr. L’s sister: “so attendance at functions, celebrations even funerals was impossible unless someone could cover for me.” There is pathos in the case of Mr. F’s sister who regrets that she cannot even “go to visit my children in KL [and must] miss so many weddings, celebrations etc.”

Generally, the reason for this arises due to the inability to leave the person with a disability alone. A replacement has to be sought to take care of the person but in many cases it must be someone familiar with the disability. More importantly, it must be someone that the disabled person acknowledges, accepts and allows to care for him/her. As Mr. L’s sister explains, “he cannot be left alone too long; he becomes delusive, sees hallucinations. [At] moments like this someone must be around to calm him down . . . he’s used to me and my parents only so even to take a bath we have to take turns.”

#### *9.4.3.2. Travel Plans Require Careful Planning*

As the brother of Mr. G notes: “family trips [and] excursions [have] all [been] stopped because [we] can’t leave him alone and go.” However, aside from not being able to

leave the disabled sibling alone for reasons already described, another issue when it comes to travelling is that the disabled person's mobility is restricted in many ways. Additional facilities may be needed, special equipment may be required and contingency plans must be rehearsed. Therefore, travelling with a person with a disability may not be easy depending on the extent of the disability and, more so, the availability of required facilities. "Even when we want to plan for any family trip/vacation, we must plan whether it will be convenient to him (Mr. D). Otherwise, the plan needs to be cancelled." This is applicable even for a local outing, as Ms. P's brother says: "sometimes want to bring her . . . out [we] need to check whether those places have disability facilities etc. . . . [and] check whether [it's] suitable for her to go."

#### *9.4.3.3. Trauma*

The sister of Mr. H describes the sacrifice as "emotional and physical trauma" and shares that "the strain of having to care for someone of such a disability is overwhelming." The brother of Ms. K [a mentally depressed person] refers to the mental strain of "the effect on our feelings, our lives . . . what we brothers and sisters underwent seeing a sister turning half mad, life for the family was a nightmare." Stress was also encountered in the sensitivities of the person with a disability, as the brother of Mr. M explains: "we had to always take care of his feelings as he was a very sensitive person . . . we had to console him when he was down and hurt [including] sacrificing some of the things we would have loved to do [but] which we know he cannot participate [in]." The expectations of the person with a disability can also be traumatic as Mr. G's brother describes:

*He is depressed about his dilemma. There are no parents to console him. He expects a huge amount of compassion but each of us siblings have our own families to worry*

*about and our jobs . . . no job means no income at all . . . but he feels we are not concerned enough about him.*

From a physical viewpoint, Mr. F's sister explains "I'm also growing old so cannot work like I could in my younger days. Carrying him, cleaning him etc. can take a toll on me."

#### *9.4.3.4. The Delay Factor*

The brother of Ms. J expresses his annoyance that "when you take [her] to hospital [you] . . . must wait very long sometimes 3 to 4 hours and I'm also a sickly person on medication but what to do?[We] have to wait."

#### *9.4.3.5. A Positive Note*

In the midst of all these sad and heart-wrenching comments, it was wonderful to hear the soothing words of Ms. I's brother:

*All siblings are always attached to her and love her so much. Especially the twin brother. He goes extra miles to provide her with a comfortable Bantex model wheelchair which is costly. All her sisters do take turn to take care of her during festivals, weddings or celebrations. It is hard, as the thought of someone in this condition at home always limits one's happiness.*

However, in spite of all the sacrifices, the overriding message in all of the interviews and in the connotation of the words in all of the transcripts was that they (the sibling) will never abandon their caregiving responsibilities because of their love and affection for the person with a disability. The common quote in almost all the transcripts was "I'm not complaining" or "I'm not grumbling." As Mr. L's sister sums up: "it's not his

fault but [the earlier details of the sacrifices was] just to make it clear for you as to what we endure but believe me we love [him] so it's done ungrudgingly.”

## **9.5. SCHUMACHER’S FOURTH PRINCIPLE**

Schumacher advocates the blending of advances in science and technology with ingredients of human values, moral awareness and ethics so that the resultant product will be satisfying and nurture wellbeing for everybody. Therefore, when the Government is effecting a policy or change, it must benefit the citizens of the nation. Schumacher beseeches the government to carefully evaluate what should be done for its subjects, and endow them with benefits that will assist them directly. Government should introduce relief which is effective in abating the problems of citizens and contribute through channels that will reach the needy.

He writes:

*There is nothing more difficult than to be aware of one's thought. Everything can be seen directly except the eye through which we see. Every thought can be scrutinised directly except the thought by which we scrutinise. A special effort, an effort of self-awareness is needed — that almost impossible feat of thought recoiling upon itself: almost impossible but not quite. In fact, this is the power that makes man human and also capable of transcending his humanity (Schumacher, 1997 at p.54)*

Therefore, government should not just dish out benefits and feel good about it, but instead ensure that the ultimate objective of introducing that benefit is achieved: that it is addressed to the person for whom it was meant and that there is some assurance that the recipient will actually benefit from it. The themes associated with this principle are

those of whether a tax relief would have been useful for a sibling caregiver and who should be the recipient of such a relief.

#### **9.5.1. Would Tax Relief Have Been Useful?**

The affirmation was resounding! There were many confirmatory expressions of “definitely!” and “of course!”, together with some polite indications of “that would be helpful” and some plain “yes” answers. The brother of Mr. D, in total support of such relief, recalls that:

*My brother's life could have been uplifted through the provision of specialized equipment, he could have gone places with sufficient facilities ...all this could have been furnished if we had the money. Although in my brother's case he's gone now but this is not an isolated situation, it is common. So another brother caring for his disabled brother, if he has to pay less tax means he can use the savings for uplifting the life of his disabled sibling, so of course it's good.*

However, some respondents did not understand the implications of tax relief. Therefore, the mechanics of how tax relief works (i.e., that essentially their chargeable income subject to tax will be reduced and in consequence their tax payable will also be less), were explained to them. Tax relief would result in less cash outflow through tax payments and create a monetary savings for them. Once the concept was explained to them, all were fully agreeable to the introduction and implementation of such relief for sibling caregivers. The study clearly indicated that there were no naysayers and that everyone was in support of tax relief for sibling caregivers.

The quantum of relief was never discussed but, as the sister of Mr. L, remarked: “I guess any genuine gesture on their part [meaning the Malaysian government], no matter how small, will be appreciated. You know, an indication that you care is in itself so nice.” Similar feelings were expressed by the brother of Ms. I: “some effort by government, even not much but they provide some assistance would be appreciated.”

The views of the respondents correspond to those of Schumacher, who beseeches government to carefully evaluate what should be done for its subjects, and endow them with benefits that will assist them directly. Government should introduce relief which is effective in abating the problems of citizens and contribute through channels that will reach the needy.

#### **9.5.2. Who Should Get The Relief?**

There was consensus that sibling caregivers should be given tax relief. In one comment on the present relief being given only to caregiving parents and children of persons with disabilities, the brother of Mr. D exclaims, “what is the use for me then? . . . my father’s income is not sufficient to support our entire family . . . they were relying on me for money. My brother is not married. So what’s the point?” The sister of Ms. B and C rebukes “what about the caregiving brothers and sisters . . . are we not human? . . . I am surprised, very surprised that our government which is forking out millions to help world tragedies is not looking after its own.”

Further, the brother of Ms. I explains: “we brothers and sisters are paying for all the expenses of taking care of Ms. I . . . so it will be better for tax relief to be given to us rather to our parents as [there is] no value for them.” The sister of Mr. L adds that their “parents’ pension is exempt from tax so they don’t need a relief [and therefore] it’s only useful for me.”

Irritated respondents question “but in the first place that’s silly; why assume that a sick or invalid person is only taken care of by his parents, spouse or kids, why we are not family?”

The inequity is expressed by the brother of Mr. M: “that’s not fair as my parents’ [are] earning less [i.e., their income is not in the taxable bracket] and there is no need for them to have these reliefs. I would have benefitted from the relief instead as I was supporting the costs for my brother.” The brother of Ms. N agrees and states “although I guess I can manage now, but I am sure there are many in a similar situation like me (i.e., taking care of disabled siblings) yet they are not recognised. We are not expecting accolades and praises but don’t discriminate[!]”

The point is driven home in the poignant words of Ms. K’s brother:

*So after father and mother are not around or cannot take of that child, how? Government going to take care [is it]? Of course siblings have to step in. Blood is thicker than water you know. Now we siblings are also old already but at least we place her at a home where we make sure she is treated well, visit her often, call her everyday ask what she needs. Put in home also costly you know.*



The other issue raised was who should get the relief. After all, argues the sister of Ms. S, “for me [it’s] no use right? I don’t pay tax. But the government should give it to my husband who is supporting me financially and indirectly my sister.” She asserts that “there is no use in specifying relations. They should look at the ultimate finance provider and peg the relief where it can be claimed, if they are sincere in awarding such reliefs. There is no rip-off, come and check. I took care of my sister as long as I could. Now I can’t manage so I’ve placed her in a home. You know my pension is insufficient, so where does the money come from? My husband of course, so give him the relief.” The same sentiment is expressed by the sister of Mr. F when she questions, “I don’t pay tax . . . but my daughter does. Can I pass it to her?” A similar scenario is presented in the case of the brother of Ms. J. who rationalises that since “my four sons contribute to the family [and he confirms that they are paying taxes]” therefore, “if the brother has no tax to pay then it must be for the person who is actually bearing the cost. Like now my sons support me and my wife, I mean our pension is not much, so they should be given a relief from tax.” This opinion is also shared by Ms. S’s sister when she remarks “the government should give tax relief to the ultimate bearer of the costs and expense. That is fair and just.”

The brother of Ms. R had another interesting view. He advocates that tax relief should be given to caregiving siblings, but argues that the recipient of the caregiving should not be confined to the person with a disability. “You see, not only the disabled persons need help. Sometimes you have siblings who are slow learners, not very healthy like with a weak heart so they tire easily etc. and these people cannot go to work and in many cases do not get married due to their ‘ailments’, so after their parents’ time or even at a stage when the parents have no income, who takes care of them but their siblings!” Therefore,

he feels that tax relief should be extended to such siblings provided “there is evidence that the siblings are taking care of that person in the form of [incurring] expenses [on their behalf] and the authorities can actually conduct a home audit to verify the authenticity of the circumstances.” He argues further “in fact in many countries, reliefs are given for anybody you take care of, not only immediate relatives”

## **9.6. SCHUMACHER’S FIFTH PRINCIPLE**

The need for a human element in all technological advancement in the fourth principle is expanded in the fifth to illustrate that this should translate into economic progress for the people and serve to uplift their wellbeing.

Therefore, the fact that the caregivers of the disabled have a 24/7 job and the recognition that no amount of technological progress can replace the human factor in the caregiving process provides an excellent argument to pursue further extended tax relief for caregivers to include those bearing the financial burden of this caregiving activity.

This principle is closely linked to the emerging theme of the cost factor

### **9.6.1. The Financial Pinch**

Financial factors can also rear their heads and create difficult moments for the siblings. Mr. E's brother remembers the awkwardness he faced "during the period [when he had exhausted all] the money to help my brother and I [had to] borrow money from friends."

The brother of Ms. N notes that the additional costs of caregiving slowly deplete financial reserves and so comments that "[since] there [were] no savings, no additional money [was available for] for leisure then." The sister of Ms. S also notes that "it didn't seem difficult then for I was still working and had a stable income, [but] today my only hope is my husband" [to bear the costs of caregiving for her sister].

The lamentation of the additional cost in caring for a disabled sibling was literally thunderous throughout all the stories, with cries such as "I am the sole breadwinner . . . it's not easy" (from the sister of Ms. B and C), permeating throughout. Others have numerous financial commitments, as Ms. N's brother explains: "apart from taking care of my family, my father also had to sponsor his brother's education as well as give a financial contribution to my grandparents."

The various types of costs incurred by caregivers are detailed below.

### **9.6.2. Medical Cost**

The primary worry was that of the cost of medical treatment and hospitalisation. The general opinion is that "medical cost is high" (as stated by the sister of Ms. B and C).

She continues that “with the OKU card there is some benefit but in government hospitals we still have to pay a minimum amount if inpatient treatment.”[However if] “they were admitted ... I [have] to pay; it’s not easy . . . it’s expensive [because] some medicine [is] free [but] some [others] have to be paid for.” Mr. G’s sibling, in explaining his dilemma of caregiving for his brother says:

*... medical costs are not cheap. He has a flat (low cost) and some savings. He [used to] get an average income of RM1,200 after his overtime. We are in the midst of applying for SOCSO [social security] assistance as every week he has to go thrice for his dialysis and each trip costs him RM120. All in he has to pay RM360 per week and his monthly cost is RM1,440. This is really a burden and this is not inclusive of other expenses such as his transportation, medication and doctor’s visits.*

The brother of Mr. D echoes that “medical treatments cost a lot”, while the brother of Ms. I exclaims that “money has never been an ending issue as whenever we take her [for] Chinese medicine and other commercial health product, we need to spend almost half of our saving.” However, at the same time, the sister of Ms. S admits “the good thing about the government hospital is that the medication is free and since she has a long history of mental illness, the doctors give good medication which is very costly.”

The brother of Mr. M adds: “money was a big issue . . . [not only for] medical expenses [but also] costs to repair and adjust parts of his shoes and other routine expenditure were high . . . equipment [to help him walk] was not cheap either.”

### **9.6.3. Engagement of a Maid**

The employment of a maid or helper becomes an absolute necessity once the sibling is just not able to cope with caregiving responsibilities on top of existing family

commitments. “I did employ a maid to take care of her at home while I’m working. [The] maid helps her to change pampers and bathe [her]”, says the brother of Ms. P. The sister of Ms. B and C explains that:

*. . .after my mum passed away . . . [and] my dad passed away, I was having health problems handling them on my own[;] pressure and chest pains, till my relatives convinced me to take a maid. I feared as the diversity of the maid and the horror stories of maids abusing kids were widespread. But I took an Indonesian maid; she was good at first then my sisters were also abused by the Indonesian maid. I sent her back then I got a Sri Lankan maid; a bit more expensive but safer. It’s a belief if they are closer in ethnic aspect, at least the chances of maid abusing kids is a zero effect. To date, I am grateful to God, the maid although not perfect in every sense, she cares well for my sisters.*

Ms. J’s brother notes the maid’s salary as a cost, as does the sister of Mr. H who acknowledges that “we had to employ a maid as the Parkinson’s disease progressed [because] it became more difficult to care for him.”

#### **9.6.4. Other Costs**

Ms. J’s brother explains that he is “a pensioner and my wife stopped work after my father passed away, to take care of my sister so it is expensive like transport to take [her] to hospital, for blood tests, pampers and other routine stuff like food, clothes . . . [plus] she needs some extra nutritional food sometimes. Everything you touch is money.” The necessity for this is voiced by the sister of Ms. B and C when she retorts “ensuring they have the right diet and supplements and yearly blood tests [is] so that they don’t face health complications”, which will be an added cost!

#### **9.6.5. Insurance Policies for Persons with Disabilities**

The sister of Ms. B and C cries: “insurance companies do not cater for the OKU crowd, that’s unfair but it’s a sad fact; a sad commercial fact.” This predicament ensues with Mr. D as well when his brother “wanted to apply for medical insurance for him but [his] applications were rejected on grounds that he was disabled person since young age.” This prompted him to question “I wonder if insurance is not helping those disabled, what the purpose of the insurance money is then?” This was also in the case of Mr. M, whose brother remarks “besides that he was denied insurance coverage as his disability was from birth.”

#### **9.6.6. Registration with the Department of Social Welfare**

Some of the siblings were able to register the person with a disability with the Department of Social Welfare. The sister of Mr. F successfully “registered him with the welfare department and received RM 300 a month which was used for his pampers and special milk powder etc.” However, achieving registration with the department has been a long and arduous journey for some.

The brother of Ms. I tells his frustrating story: “There were no support from the local welfare bodies or rather they [were] not concern[ed with] . . . her case. As we tried to register her lately to [the] welfare department, there were many formalities. I need to produce medical report from the doctor and other documents. I wrote to [U]niversity [H]ospital and they gave a one page report and barely nothing that we understand. And I

was told by the welfare office to get a medical check-up for Ms. I and then to proceed with application. I went to Tampin hospital and meet with one of the doctor and explained Ms. I's situation [i.e., that she could not be brought to the hospital easily] and persuaded the doctor or other doctors to pay a visit to confirm her condition, with transport cost paid for[;] however . . . the doctors [were] reluctant and prefer to be bureaucratic follower[s]. At last all the family members decided to bear the cost all the way through which has been from the start.”

This traumatic experience was similar to that of Mr. M where his brother states: “although we went numerous times to Jabatan Kebajikan Malaysia [the Department of Social Welfare], to help fund the equipment [to assist him to walk], they were not much of a help . . . a lot of procedures we had to go through to get a fund, but we were denied at last.” This also is the case for Ms. S, whose sister says “I did try to get help from the Department of Social Welfare . . . but they refused saying that she is not an OKU.”

#### **9.6.7. Placement in a Home/Institution**

As discussed in section 3.4, certain circumstances necessitated the placement of the person with a disability at an institution or home for persons with disabilities. This additional cost is borne by the sibling and at least equates, if not exceeds (in fact in most cases it does), the cost of caring for the person with a disability in one's own home. This is therefore an additional cost borne by the sibling caregiver. This is evident from the testimony of the brother of Ms. K who reports that the “monthly cost was RM 700 per month now as she was admitted to the home.” The burden of cost is obvious from the

words of the sister of Ms. S: “today I find it difficult to pay for all the expenses incurred during her stay in the home for I live on a pension.”

However, even those who do not feel the financial pinch to be painful nevertheless realise that sacrifices are made, as the sister of Mr. L confesses:

*Yeah I guess we can afford it but remember there were additional costs for medicines, special food supplements etc. and these were necessities not luxuries, so yeah we have to get them it's not a choice but the income is fixed mind you; so cuts have to be made elsewhere. And not everything can have a price you know, like what we have to sacrifice; what value do you attribute to that?*

Contributions by other members of the immediate family are also recognised. As the sister of Mr. F states: “other family members also contribute what they can . . . and [so does] my daughter [who] is working.” Ms. P’s brother also thankfully acknowledges that “luckily some of my relatives did [give] some financial support to help my sister” at a time when his sister “need[ed] to have operations . . . [to]adjust her back bone and try to use other [bone parts] to replace the broken one, etc . . . . that really [cost a lot].”

#### **9.6.8. Summary of General Costs Incurred by the Caregivers**

The nature and quantum of costs incurred by the sibling caregiver are categorised summarily in Table 9.1 below.



**Table 9.1**  
**Summary of Monthly Costs Incurred by Sibling Caregivers (in Ringgit Malaysia )**

Nature of expenditure Person with disability	Medical treatment / medication	Transportation	Vitamins & food Supplement	Pampers / pads	Maid or Home / Institution	Others
Ms. B & C	250				450	
Mr. D	300	300	350	600		
Mr. E	500	500				Various <sup>1</sup>
Mr. F			220	60		
Mr. G	1440	500	500			Various <sup>2</sup>
Mr. H		150	170	600	700	
Ms. I				150		50 <sup>3</sup>
Ms. J	100	Varies		50	650	
Ms. K					700	
Mr. L	550		250			
Mr. M			220	60		
Ms. N			540	288		400 <sup>4</sup>
Ms. P			200		600	
Ms. Q	25	100	250	100		
Ms. R	25	200				100 <sup>5</sup>
Ms. S	Nil			100	500	

<sup>1</sup> Traditional treatments (Ayurvedic/Chinese massage) ad-hoc per treatment is approx. RM 5,000.

<sup>2</sup> Other medical treatments (up to the date of the interview) approx. RM 2,000.

<sup>3</sup> Toiletries.

<sup>4</sup> Clothes and toiletries. Personal care was indicated as “priceless.”

<sup>5</sup> Monthly allowances given by the brother for her personal expenses.

As is evident from the above analysis, the major lament of sibling caregivers is the cost factor. Although this has not discouraged them from undertaking the responsibility of caring for their disabled sibling and they have remained accountable, it is the role of the state to not only inculcate this sense of accountability but also to ensure that it is perpetuated. For this, in line with Schumacher’s philosophy, the government must ensure that any assistance given (e.g., tax relief) is relevant and sufficient to meet the needs of those who have undertaken a part of the state’s responsibility to care for persons with disabilities.

## **9.7. SCHUMACHER’S SIXTH PRINCIPLE**

In this last principle, Schumacher discourages progress that is segmental i.e. enjoyed by some but not available to others. He advocates a harmonisation of practices whereby the progress is enjoyed by everyone, something that permeates through and nourishes every person in society.

Therefore, the non-recognition by the Government of the sacrifices made and problems faced by siblings of the disabled which in turn has pushed this category of people backward, especially in terms of financial prosperity, is an issue requiring urgent address. Schumacher says “the way in which we experience and interpret the world obviously depends very much indeed on the kind of ideas that fill our minds.” Therefore, knowing that such relief is available in neighbouring countries creates dissatisfaction and disappointment with our government and has a wave effect on all other actions. Harmonisation of tax laws should be one of the focus points of the administrators of the nations in a particular geographical region

This corresponds with the theme of response to Singapore providing tax relief for sibling caregivers as discussed next. The spontaneous awestricken remark by Mr. E’s brother served to start the discussion: “Wah! Why [doesn’t] Malaysia . . . have this? Singapore government really helps their people.”

### **9.7.1. The View**

A variety of emotions and thoughts were shared. They included a simple “that will be good” by the brother of Ms. N, and the obvious question of “well if in Singapore there is a tax relief for siblings why not in Malaysia?” by the sister of Mr. H. Ms. K’s brother would welcome its “introduction in Malaysia, [and asked that] if Singapore can do it why Malaysia cannot? After all we always say ‘Malaysia Boleh’ [a term constantly flaunted by the government to show that what others can do, Malaysia also can]!” Mr. M’s brother exclaimed: “yes it should be introduced in Malaysia. There are a lot of siblings that take care of their brothers and sisters and yet not being able to enjoy such reliefs. So I strongly believe that such a relief should be implemented as soon as possible.”

#### **9.7.2. The Frustration**

Disappointed, the brother of Mr. D [who is deceased] rebukes, “we are always behind; but now it’s not too late. Funny nobody thought of it earlier.” “Really?”, asks the sister of Mr. L. “Just a strip of water away and these guys can’t catch the importance of the fact. I hope your study here will be productive in influencing them, otherwise they must be blind!” Ms. I’s brother suggests to “give it to the caregiver, [there is] nothing to hide; you can see daily who takes care [of the person with a disability] and who [is] supporting them financially.” The brother of Mr. G, being disillusioned, reproaches: “what’s the problem, you see something useful and good you should immediately implement it in Malaysia without hesitation. I mean sometimes the government donates so much to disaster victims overseas but turns a blind eye to the sorrows of its own citizens.”

### 9.7.3. The Quantum

Recognising the variance in economic conditions prevalent in different countries, and commenting on the amount of SGD 3,500 awarded by the Singapore government, the sister of Ms. B and C comments “by the way, why follow Singapore, we should design our own incentives considering the price index , GDP per capita and inflation rate in Malaysia.”

### 9.7.4. The Consensus

The unopposed “aye!” to the legislation of such relief is explained by Ms. P’s brother: “because my parents [are] already old, now it’s me (the younger generations) who [are] taking care my handicapped sister. They should think about us.” The final spike is nailed in by the brother of Ms. Q:

*In our country also [this] should [be] encouraged . . . so that bedridden people like my sister can benefit from this scheme. This will indirectly give more encouragement to brothers and sisters to take of each other rather than put [any disabled sibling] in homes. Even if got children, sometimes they cannot take care because of work, so brothers and sisters should step in if can, and this would be an incentive.*

That concludes our discussion of the emerging themes viewed through the theoretical lens of Schumacher. We now proceed to the theme of religion supported by the philosophy of the Vedas.

## **9.8. RELIGION**

The numerous principles, values and beliefs expounded in the philosophy of the Vedas has been discussed in detail in chapter four. Here we will deliberate on the emerging theme of religion.

The general consensus among sibling caregivers was that religion did play a part in influencing their intention to undertake the caregiving responsibility. The majority of the respondents were of the Hindu faith and attributed their undertaking to their religious upbringing and the spiritual values taught and instilled in them throughout their lives.

### **9.8.1. The Hindu Faith – The Duty of Care**

As Mr. F's brother confirms, "religion always says do good and it's my duty to take care of my brother. I mean who else is there? I don't hate the job [and] I love him very much." Mr. G's brother informs that "man is born with both the good and bad characteristics [therefore] when the religious values are taught and drilled into you fervently, the good in you surfaces and submerges the bad. Therefore, the good virtues of care, love [and] affection shine and cause you to be more humane." The sister of Ms. Q endorses that the "Hindu religion [advises] people to help those needy people. I believe that this is law of karma. Maybe in previous life my sister helped me; in this life I help her back . . . my religion encourages us to do good things, so that we can achieve better life in the next birth or achieve moksha." Ms. K's brother explains that "our religion [Hinduism] states that whatever happened, [is] happening and [is] going to happen is [based on]

our past deeds (good or bad karma) so we have to live with it [with] no escape.” He adds: “helping anyone in need is a good service [and] ‘Service to mankind is a service to God’.”

#### *9.8.1.1. The Hindu Faith – The Respect for Persons with Disabilities*

Others went a step further and advocated that society as a whole should understand that persons with disabilities are also humans and should be treated with respect in line with the teachings of all religions. The sister of Ms. B and C feels strongly that the public should not discriminate against persons with disabilities. She states that “Malaysians must learn to accept and love the disabled not neglect them or shun them. Everyone is a child of God.” She tries “to educate the ignorant ones” because, she argues, “what’s the purpose of trying to do charity in an organization or on an auspicious day” when you don’t accept everyone as equal? Mr. L’s sister also offers that “there is not [a single] religion that tells [its followers] to mean harm for others. We are all God’s children, it’s just that due to our past karma we see people suffering, being disabled etc. We are here to do good, even if we don’t at least we shouldn’t harm, make fun of another person. We are all answerable to someone superior to us one fine day.” The sister of Mr. F suggests that “if [from a young age] . . . children are inculcated with religious notions of caring for the handicapped and less fortunate then . . . they will take care or at least show compassion and help in some way.”

### *9.8.1.2. The Hindu Faith – As Comforter*

Religion was also used as a comforter in times of distress, as a comforter in moments of grief and as a relief in periods of pain. The brother of Mr. D acknowledges that “all religions teach you to help the disabled.” In rationalising why “God only gives this type of child [meaning a child with disability]” to certain parents, he remembers the story told by a “family friend, a doctor, [who] told that ‘GOD had given you this type of child (or brother), so that you will take care [of] him very well compared to others . . . that’s why GOD had sent Mr. D to your family. May be this [is] GOD’s wish’.”

### *9.8.1.3. It is Not Religion but a Sense of Duty*

Not everyone, however, shared the view that religion was the influential factor in caregiving. Some felt that the main reason and motivation for taking on the caregiving responsibility was either a sense of duty, or sheer love and affection for the sibling.

The brother of Ms. J explained that although “all religions teach good and helping others”, in his case “it’s more of caring for my sister . . . I mean she’s my sister ... so ... it [is] not just religion.” Although he admits that religion “may have influenced [his action] but it is more [out of] affection I guess. It’s another life right? . . . so more of humanitarianism . . . religion advises [us to care for the less fortunate] but it’s the duty of a human being [to] take care.”

Similarly, the brother of Mr. M remarks that “although my religion teaches to love and care, I always felt it is my duty and responsibility to take care of him as a brother.” In a further response he offers: “every religion does teach an individual to help the less fortunate, and it certainly does have a strong influence in moulding a person’s character [but although] it could have played a role . . . it’s more of my love for my brother; more than religious beliefs I guess.”

Interestingly, Mr. G’s brother also states that the motivation to care for his brother was “out of love of course . . . I mean he’s my brother.” He continues, however, that “the instilling of these emotions of care and love come about from the inculcation of religious beliefs and values [and therefore], indirectly, religion could be the motivator.”

Six respondents were not of the Hindu faith. Their testimonies are summarised below to explore if non-Hindus had similar views with respect to the role of religion in influencing the decision of a person to be a sibling caregiver

### **9.8.2. The Islamic Faith**

The sister of Mr. H confirms that her intention to care for her sibling was motivated by her religious beliefs. She says: “in Islam we are taught to care for the elderly, the sick and the disabled.” She also endorses that religion does have an influence in moulding a person’s



character, in terms of caring for the less fortunate. Similarly, Ms. T's brother [a Muslim] also holds the view that "religion has motivated me to take care of her but also she is my sister."

### **9.8.3. The Buddhist Faith**

In response to whether religion motivated him to take care of his sister, Ms. P's brother replies, "of [course] every religion encourages people to help others, some more [since] she is my own sister." A similar response was noted from the brother of Mr. E.

### **9.8.4. The Christian/Catholic Faith**

To gather the Christian view, the brother of Ms. R explains that "the centre of Christian faith is love, and helping her is how I show my love to her. Part of the faith is almsgiving and engaging in charitable works. This is what is written in the Bible and we walk by that virtue. And where would be a perfect place to start if not [at] home." However, the sister of Ms. S [a Catholic] states that "religion was only a small factor for I was always blaming God, then. The main reason was my mother who always taught us to be kind and caring for the other person, no matter who he/she is." She believes that "religion plays a small role" and that "the bigger role is played by our parents who are our God in our daily life." Her pillar of strength was her mother: "I have watched her care for my sister through all the hardship and still love her with all her heart."

#### **9.8.5. The General Faith**

The brother of Ms. N was of mixed parentage and religious background and so was rather reluctant to “be so specific about religion.” He continued: “however, my personal religion has definitely had a strong bearing in my intention to care for my sister. I feel honoured that God had given me this opportunity to care for a disabled child. I believe God will only give this challenge to those who He feels are able to handle this challenge.”

Schumacher advocates the principles in Buddhist economics, which amongst others, seek to maximise human satisfaction by the optimal pattern of consumption instead of profit maximization. Instead of merely providing incentives to big business and corporate entities, the government should concentrate on enhancing the wellbeing of each citizen, understand the day-to-day problems they face and appreciate the sacrifices they make.

He points out (at p.50) that there is an evident variance between economics as propounded by the Buddhist faith, and the practice advocated by “modern materialism”: the former “sees the essence of civilisation not in a multiplication of wants but in the purification of human character.” He remarks that the formation of character is highly influenced by the person’s work; work, as long as it adheres to the tenets “of human dignity and freedom, blesses those who do it and, equally, their products.”

#### **9.8.6. The Non-Response Factor**

The fact that many sibling caregivers of persons with disabilities did not want to relate their experiences is in itself a factor in support of religion, because one of the reasons provided for this non-commitment was that by disclosing their sacrifices, pains and frustrations in caring for their disabled sibling, they would lose all of the benediction and goodness accruing to them in the afterlife for this unrewarded service. Obviously their intention in providing the caregiving services was influenced by their religious beliefs.

However, another group had a rather unusual religious outlook, saying that such disclosure would nullify all the goodness that they had gained in taking care of their disabled sibling and abate their chances of achieving heaven/nirvana etc.

This links back to the Vedic conviction of giving without expecting anything in return, which raises the conceptualisation of accountability to an even higher platform that has yet to be explored and understood. The perception of what constitutes accountability has been given a new identity in this study facilitated by drawing on Vedic philosophy and viewing it through the lens of Schumacher.

## **9.9. SUMMARY AND CONCLUSION**

The revelations from this study, from both my own story and those of the respondents, strongly support the introduction and implementation of tax relief for caregiving siblings. Further, this autoethnographic study also supports the positive relationship between religion and the

caregiving function performed by siblings. The philosophical views of Schumacher are also seen to intricately weave through the findings, adding empirical rigour, injecting an epistemological element and providing an ontological justification for the introduction of tax relief for sibling caregivers.

However, this study is not just about requesting tax relief for sibling caregivers of persons with disabilities; it embarks on a journey of conceptualising accountability, and narrows it down to the responsibility of the state to care for persons with disabilities. Developed countries have established well administered institutions to undertake this responsibility but facilities for the disabled are still lacking in developing nations. That is why our neighbours, Singapore and Thailand, still place this responsibility in the hands of the family and provide good assistance, amongst which is tax relief. However, the institution of tax relief for sibling caregivers, though a start, would be insufficient. The way forward is to bring about a whole social transformation, providing not only pecuniary assistance and relief, but cultivating a strong belief system that produces a caring society based on a framework grounded on the conceptualisation of accountability.

The next and final chapter will summarise and conclude this thesis.

## **CHAPTER 10**

### **SUMMARY AND CONCLUSION**

#### **10.1. INTRODUCTION**

The purpose of this chapter is to reflect on the implications of the findings and discuss the contributions and limitations of the study as well as suggestions for future research. The final chapter is organised as follows. Section 11.2 discusses the view through the philosophical lens of Schumacher whilst Section 11.3 summarises the overall findings of this study. Section 11.4 addresses the potential implications and contributions of the study. Section 11.5 discusses the limitations of the study. Section 11.6 offers several possible avenues for further research and Section 11.7 concludes the chapter.

#### **10.2. THE VIEW THROUGH THE PHILOSOPHICAL LENS OF SCHUMACHER**

Wade (1975, pp.199-200) had summarised the themes philosophised by Schumacher, and the findings of the current study had been visualised through this theoretical lens. Commencing with Schumacher's criticism of the notion that modern economics had solved the problem of production when the free elements provided by nature are fast depleting, we can clearly see a nexus to the complacency in which the state seems to find itself with regard to sibling caregivers.

Persistent sidelining and ignoring may result in the siblings abandoning their caregiving responsibilities and returning them to the state.

Schumacher constantly reminds us that advancement in technology has limitations and can never replace human values, moral awareness and ethics. Not denying that progress is needed, he cautions however that at no time should the human element be compromised for the sake of innovations in science and technology. Therefore, the government's concentration should not only be on big companies, multinationals and investors but a caring look must always be shared with the citizens who voted them into power.

His fervent advocacy is for Buddhist economics, and he urges the achievement of satisfaction as opposed to maximisation of profits. In the same vein, the government needs to address the formulation of relief, exemptions, concessions and rebates. Allocation of such assistance to people who cannot benefit from it defeats its purpose, and a study should be undertaken to understand what would really benefit the targeted group of people. In our study, the respondents were univocally clear that tax relief should be given to the person supporting the finances of the persons with disabilities, as well as to the caregiver where the caregiver has no source of income due to having to undertaking the caregiving task.

### **10.3. SUMMARY OF FINDINGS**

The study was taken with the noble aim of conceptualising the theme of accountability, drawing on Vedic principles and viewing it through the lens of Schumacher to empirically examine the need to institute tax relief for sibling caregivers. It commenced with a take on the mammoth issue of accountability to society, condensing its values through Messner's (2009) "critical perspective" lens to understand its socio-economic impact on society at large, and on persons with disabilities and caregiving siblings in particular. The study then examined extant literature on persons with disabilities, sibling caregivers and the role played by religion in encouraging the caregiving function. Finally, the study took a critical look at the tax system in Malaysia in relation to its contributory support for persons with disabilities and caregiving activities. The findings of the study shall now be summarised from the different perspectives analysed in the previous chapter.

#### **10.3.1. Character Description of a Disabled Person**

A close relationship was evident from the praise-saturated opinions that the sibling caregivers had of their disabled brothers and sisters. Almost all the respondents held the siblings that they were caring for in very high esteem. It was clear that they exhibited capabilities which foretold a bright future, full of success and prosperity, if not for the disability. This conveys the message that persons with disabilities have great reservoirs of abilities that can be harnessed and put to good use if sincere efforts are made to understand their potential, and good thought is given to

how opportunities can be created from them. This involves some costs. Therefore, the award of tax relief to a caregiver will lighten the financial burden and serve as an impetus to find ways of improving the lives of the person with a disability.

### **10.3.2. Cost Factor**

In line with the study conducted by The Joseph Rowntree Foundation, which established that there were “additional costs relating to a person with disability”, the respondents in the current study also provided excellent testimony to this fact. Numerous contributory factors have served to enhance the financial burden of the caregivers.

Medical costs head the list. Although generally, government hospitals are free or charge minimally for medical treatments, certain medications are not available there and have to be obtained from private pharmacies together with certain facilities such as dialysis etc. which have to be procured privately. The other constraint at government hospitals is the long wait which takes a toll on the caregiver, especially when that person is also old and not in the best state of health. Augmenting this is the general comment that the level of care at government hospitals is lacking. This is understandable, however, due to the large numbers of patients seeking treatment there. The solution is a referral to private hospitals but this involves additional costs.



Aside from medical costs, another expenditure is transportation to take the person with a disability for periodic treatments. Where the caregiver can drive, the cost is that of fuel and parking. In cases where the caregiver cannot drive, transportation requires obtaining the help of others or getting a taxi or rented car, with each option involving additional costs. Yet another expense identified is that of vitamins and other food supplements essential to maintaining the person with a disability in a good state of health.

The aging or the poor health conditions of the caregivers themselves, the work pressures and inability to cope, necessitated the employment of a maid or helper in many cases. The other alternative is to place the person with a disability in a home or institution. In line with the literature (Griffiths & Unger, 1994; Remennick, 2001; Taylor et.al., 2008; Welch et.al., 2011), almost all of the respondents were against placing their sibling in a nursing home. However, as the brother of Ms. K and the sister of Ms. S explained, it was only when they really could not take care of their siblings that they unwillingly placed them in an institution with full knowledge that they could provide better care themselves. Even then, they emphasised that the sibling was frequently visited and also brought home occasionally to maintain the bond with family.

All attempts to obtain medical insurance for persons with disabilities proved futile, as clearly lamented by many respondents. They argue that if disability does not equate to a medical deficiency or illness, then why the discrimination? Registration with the Department of Social Welfare has been another nightmare for many, with loads of red tape, bureaucratic prerequisites and unfriendly reception. Many disagree with using a fixed level of income as the measure of eligibility because different families have different circumstances; different families have to

deal with different types of disabilities, and the amounts and types of expenditure incurred are also very diverse. These factors should be considered in evaluating whether a candidate should qualify for the monthly stipend provided by the Department.

All these expenses result in a constant leakage from the pockets of the caregiver, congruent with past literature where Smith et.al. (2004) explain that studies have established a relationship between financial difficulties and disability (Sainsbury, 1970; Blaxter, 1976; Hyman, 1977; Townsend, 1979; Martin and White, 1988; Grant, 1995; Burchardt, 2000; Gordon et al., 2000). However, this strain can be relieved, if not entirely then at least partially, by the provision of tax relief to the caregiver.

### **10.3.3. The Difficult Moments in Caregiving**

The study revealed the extensive impact that providing caregiving to a person with a disability can have on a sibling. As acknowledged by Yanagisawaa et al. (2010), the effect can assume the form of an “economic . . . physical . . . [or] psychological” strain. The extent of the disability influences the degree of impact; in the case of an invalid person who is unable to express himself, the strain of a communicational block is paralyzing. Lack of ability to move themselves imposes a physical strain and, in the case of mental depression, the caregiving sibling needs to have great psychological endurance in order to survive. Again, this is consistent with past literature (Abrams, 2009; Gillies & Lucey, 2006; Guse & Harvey, 2010; Hames & Appleton, 2009).

Society at large can also create anxiety for the caregivers, with cold looks, feelingless stares and constant whispering blatantly referencing the person with the disability. This is very hurtful to the disabled person, and has an intense effect on the sibling caregiver as well.

Again, although a direct impact might be difficult to visualise, a financial endowment even in the form of a tax relief will provide recognition of the pains endured and provide some valuable consolation.

#### **10.3.4. Sacrifices Made by the Sibling Caregiver**

The time factor is another complexity that needs to be handled by the caregiver, especially when the person with a disability requires constant attention. This encroaches on the life of the caregiver, literally annihilating all participation at joyful and sad occasions, relaxation or rejuvenating travel or even just having some time for oneself. This corresponds to the findings of McHale & Gamble (1989).

The study also shows that caregiver sacrifices can also take the form of giving up a lucrative pastime such as weaving, tailoring and handicraft production. While performed initially as hobbies, these had developed into sources of revenue for families but had to be shelved due to the responsibility of caregiving. Mental trauma and physical strains of caregiving are other forms of sacrifice endured by caregivers. Again, the perennial question of “isn’t some form of

appreciation due?”, raises its head. The reply obviously has to be in the affirmative, and the form suggested in this study is tax relief.

#### **10.3.5. The Impact on the Caregiver’s Work**

In line with past literature (Remennick, 2001; Bradbury et al., 2001; Gorden et al. 2012), this study also identified that the provision of caregiving has a distinct effect on the work of the caregiver. Caregivers recounted the loss of opportunities for career advancement, the need to take time off work to transport the disabled sibling to medical appointments and ad-hoc treatments, work disruptions due to emergencies, and even the complete sacrifice of a good job in order to undertake the noble task of caregiving. Surely such sacrifices should not be ignored. Although sibling caregivers rarely seek recognition, the government should nevertheless realise that these siblings are, in effect, relieving it of its social responsibility to take care of the nation’s disabled citizens. Therefore, the award of tax relief is justified.

#### **10.3.6. Religion**

The study found that the influence of religion on the choice of undertaking the caregiving responsibility ranged from being a significant factor to some respondents, to being absolutely irrelevant to others, with a third group identifying the factor as being between the two extremes. Although the majority of the respondents were of the Hindu faith, a review of literature in Chapter 4 revealed that the teachings of Hinduism, Buddhism, Christianity and Islam showed

almost no difference with respect to providing caregiving to persons with disabilities. This was confirmed in this study as well where, in addition to the respondents of the Hindu faith, two each of Muslim, Buddhist and Christian respondents, as well as one other respondent who expressed that his religious inclination did not fall squarely into any of the above religions, participated in the study. The opinions of the non-Hindu respondents did not show a variance with the views of the Hindu respondents.

Generally, all the respondents of the Hindu faith (with the exception of the sibling of two respondents), acknowledged that religion was the guiding light that inspired them to undertake the caregiving responsibility. They attributed it to an opportunity to wipe out their Karma, a chance to practice what they had learnt in the scriptures and holy books and viewed it as a prospect to break loose from the bondage of “samsara” (re-birth). A similar opinion was expressed by the Muslim and Buddhist respondents, one of the Christian respondents and the respondent who professed “a personal religion.”

However, two Hindu respondents opined that it was more out of a sense of duty, or rather sheer love and affection for the disabled sibling, which prompted this decision, not religion. They felt that the undertaking was based on humanitarianism, devoid of a religious attachment. The other Christian respondent also attributed the impulse to care for the disabled sibling to her mother, stating how she steadfastly faced all obstacles and difficulties to care for her sibling and “loved her with all her heart.”

Another sibling in the study provided a third perspective. He agreed that the assumption of the caregiver role was based on the love for a brother and undertaken as a duty towards a family member. However, he argued that this was cultivated through years of staunch religious upbringing and inculcation of theological principles which had planted the sense of duty and love in the hearts of the siblings.

#### **10.3.7. The Current State of Welfare in Malaysia**

As Doessel & Williams (2011) recognise “Government policy can alleviate inequities in living standards”, but they emphasise that there are certain “key variables to which government should direct attention” so that it can “alleviate both horizontal and vertical inequity” through the disbursement of “grants to disabled people.” However, the general opinion in this study is that there is massive room for improvement in the current state of welfare in Malaysia. Although acknowledgement is made of free medical treatment at government hospitals and reserved seats and parking areas for persons with disabilities, the clamour for more is not out of greed but rather necessity. A whole range of suggestions for improvement are detailed in Chapter 10. The stories of pain and anguish are widespread, and the consensus is that “it is better for us to take care of our disabled siblings.” However, the perpetual issue of funding arises. In the search for a solution, every respondent was asked if tax relief would be appreciated. The responses are detailed below.

#### **10.3.8. The Award of Tax Relief for Sibling Caregivers**

Studies by Yanagisawaa et. al. (2010) have shown that “Government policy had a crucial effect on sibling caregiving. However, in many developing countries, statutory support for orphans is not well-established or not well-functioning. Communities recognized that their support was not sufficient and that government commitment is necessary.”

Those who did not understand the implications of getting tax relief asked for clarification. The unanimous reply of those who knew what tax relief was, as well as those who did not but knew after clarification, was an unqualified “yes”. The fact that similar relief was awarded across the border in Singapore prompted most respondents to insist on its introduction and implementation in Malaysia.

With this summary, the implications of the study will now be discussed in the next section.

#### **10.4. IMPLICATIONS OF THE STUDY**

The implications of this study will be examined by aligning the findings of the research with the research objectives propounded at the beginning of the study.

#### **10.4.1. First objective: to understand what motivates siblings to become caregivers**

The study has succeeded in explaining what motivates siblings to become caregivers of persons with disabilities. Although it is the responsibility of the state to care for these people, this duty has slowly been delegated to members of the disabled person's family. However, with the demise of their parents and where the person with a disability does not have a spouse or children, the siblings have to step in to undertake the caregiving function. They recognise a sense of responsibility towards the disabled sibling and feel accountable for their wellbeing. A sense of duty draws them towards the acceptance of the role. Therefore, although a clear indication is not available, generally the crucial motivating factors seem to be a sense of accountability and the religious upbringing within the siblings themselves. This leads to the second objective as discussed below.

#### **10.4.2. Second objective: to develop a theoretical conceptualisation of accountability drawing from Vedic philosophy**

The concept of accountability is vast, as is obvious from the literature, transcending a universal definition, surpassing the drawing of boundaries and extending beyond into a vista of possibilities. In this study, however, the motivation to undertake the caregiving responsibility has been explained using the principles enshrined in Vedic philosophy, in line with the concept of Karma and also a sense of duty as prescribed in religious literature.



Accountability is a wide, universally encompassing and pervasive concept. The discussion in Chapter two shows its ubiquitous permeation into a vista of areas. This study concentrates on the accountability of the Government to the society that had voted it into power and precipitates it down to their responsibilities to caregivers with the suggestion that the endowment of tax reliefs for sibling caregivers would facilitate the discharge of this responsibility.

The ability of the caregiving sibling to bear the trials and problems associated with the caregiving role and continue with a positive exuberance has, in many cases, been attributed to their religious upbringing and the strength of their faith and belief. This provokes the need to conceptualise accountability from a theological viewpoint. Although attribution of the motivation has been diverted from a theological source and clarified as being born from compassion and love, it is obvious that these qualities are imbibed by a person from exposure to theological and religious knowledge.

Based on the detailed discussion on Hinduism, the essence of which is the Vedic philosophy, persons with disabilities have generally resigned to fact that this is part of their Karma, an action-reaction play based on wrongdoings in their past lives. Some view it as a form of retribution, payback time if you may, but others have taken an optimistic view; a chance to progress, an occasion to display their unwavering devotion in spite of the infliction or just an opportunity to clear their cycles of rebirth and achieve enlightenment.

For the caregivers, the Vedas have opened up a vista of positive views. They explain that the placement of the disabled person in their care has made them a member of the selected elite endowed with the opportunity to wipe out their karma. It furnishes them an avenue to demonstrate the free distribution of love and affection and a possibility to do charity, both being fundamental principles in Vedic philosophy.

However, this conceptualisation needed a theoretical lens to enable its effective portrayal and this was achieved with the use of Schumacher's philosophy, as seen next.

#### **10.4.3. Third objective: to examine whether the motivation can be explained from an accountability perspective using Schumacher's philosophy**

Schumacher emphasises on the wellbeing of the citizens of a country, their contentment, and their sense of enoughness and satisfaction, as an indicator of prosperity without undue reverence to achievement in growth, expansion and development. Similarly, a majority of the siblings in this study have expressed a sense of duty, an unwritten obligation, and an unenforceable warrant of responsibility to care for their disabled sibling instead of admitting them to an institution, although it comes with a mammoth bill of sacrifice. However, in line with the principles enunciated by Schumacher, that "small is beautiful", there is something in the siblings which generates an accountability and a passion to care for their disabled brethren at the expense of their own personal development, their families and their financial prosperity. One should not lose

sight of the fact, though, that this is the responsibility of the government, which leads to the last objective of the role of the state.

#### **10.4.4. Fourth Objective: to explore the state's role**

With the motivation having been explained, the conceptualisation of accountability was then used in evaluating the role of the state (which had delegated the caregiving role to the families), in inculcating the accountability concept in society. The state is indebted to sibling caregivers for undertaking that role and has a responsibility to assist them in every way possible. An avenue for discharging this responsibility was seen in the tax system through the offering of tax relief, rebates, incentives and other forms of assistance. The theoretical basis for this study was further strengthened through the use of the philosophical lens of Schumacher.

The undertaking of the caregiving responsibility has quantitative implications in terms of the additional financial burden laid on caregivers. It also has qualitative implications which it is agreed cannot be obliterated through a financial endowment, although the latter will provide an emotional and psychological reprieve for enduring the qualitative burdens of caregiving. The study has provided the opinions of siblings caring for persons with disabilities: they have expressed affirmative opinions that the introduction of tax relief for sibling caregivers would serve to either directly or indirectly alleviate the burden of caregiving. After all, the best way to gauge the basis of accountability and rights is to seek the opinion of the general public (Gray, 1990; Malachowski, 1990).

However, the discharge of its accountability through the institution of tax relief for siblings of persons with disabilities should be undertaken effectively. Three distinct factors clearly emerged from this study. These include: 1) who should be the recipient of the tax relief; 2) the concept of caregiving as a prerequisite to claim this relief, and: 3) the quantum of relief provided.

#### *10.4.4.1. The Recipient of Tax Relief*

All the caregiving siblings who were working and paying tax on their income were agreeable to the tax relief being given to them. They understood that this would result in a tax saving for them, which indirectly translates into a reduced cash outflow, resulting in the availability of more funds to ease the additional financial burden of undertaking the caregiving responsibility.

Those sibling caregivers who were not working, or who were earning income below the taxable income bracket, did not see the use in receiving such relief. However, since their income was very low, it was supplemented by contributions from their children or other siblings. Therefore, they reasoned that the recipients of the tax relief should be these contributors and not themselves.

#### *10.4.4.2. The Prerequisite to Claim Tax Relief*

With the exception of one respondent, this study concentrated on siblings who were caregivers of persons with disabilities. Therefore, the general objective at the start was to justify a claim for siblings who took care of persons with disabilities. However, in the course of the study, an interesting issue arose from the interview of one of the respondents selected through the

snowball sampling method. The respondent was taking care of a sister who was a slow learner. She was not able to advance very much in her education and she was not able to hold down a job due to her lacking capability, which was not tantamount to being disabled. The sibling's argument was that although she did not come within the ambit of the definition of person with a disability, she could not earn a living, and so had to be cared for. He draws a parallel between a normal child and a disabled child. The government provides relief to both categories knowing that they cannot fend for themselves, albeit it provides lower relief for the former and higher relief for the latter in recognition of the additional costs in taking care of a disabled child. Similarly, the respondent argues that the same concept should be applied in the case of adults who are not disabled but who are unable to work due to a lack of capability.

#### *10.4.4.3. The Quantum of the Relief*

Based on the argument in the preceding sub-section, the suggestion in this study is that structured tax relief should be awarded in Malaysia. The amount should be higher where the sibling is taking care of a person with a disability, and lower in the case where the sibling is not disabled but nevertheless unable to fend for his or her self due to genuine inadequacies or lack of capabilities.

With an understanding of the implications of the study, the limitations of the study are acknowledged next.

## **10.5. LIMITATIONS OF THE STUDY**

The study results are subject to a few limitations. The main limitations of the study are identified as follows:

1. The theoretical foundation for this study was based on the principles enshrined in the Vedas and the lens of Schumacher's philosophy. Although it has been established that Hinduism was the oldest religion but nevertheless a different perspective may have arisen by perusing the philosophies expounded in the sacred scriptures of the other religions.
2. The study provides empirical evidence to support the advocacy of tax relief for sibling caregivers but the perspective engaged was from that of the sibling. It would be fulfilling to embrace this advocacy from the viewpoint of the State i.e. in illustrating that in terms of cost incurred and benefits derived, it would still be advantageous to implement this relief.
3. As with all qualitative studies, the objective is to provide a rich description of the issues being researched and paying particular attention to specific matters such as sibling caregivers of persons with disabilities in this study. Although interviewing seventeen siblings was sufficient to illustrate that a point of saturation has been reached, nevertheless it may not permit a generalisation of the findings to a wider population.

The limitations enable us to put forward good suggestions for future research, which is addressed in the next section.

## **10.6. SUGGESTIONS FOR FUTURE RESEARCH**

The extension of the current study is possible in the following areas:

1. The number of respondents could be increased, providing for a variation in racial and religious composition, different geographical locations, and different income levels and based on the gender of the sibling.
2. Future studies may want to consider the award of tax relief in countries other than Singapore and Thailand.
3. The advocacy in this study was for the introduction of tax relief for sibling caregivers. Extending this relief to all caregivers could be attempted in future studies.
4. The study drew only from Vedic philosophy and Hinduism in general. Future studies could extend the coverage to other religions and investigate the effects.

## **10.7. CONCLUSION**

The present study was pursued as an attempt to justify the introduction and implementation of tax relief for sibling caregivers. A concerted endeavour has been undertaken to convince the relevant authorities and the government in general, that this is essential. First, to abate the caregiver's financial burden. Second, as recognition of their service. Third, as a form of compensation for their sacrifices, and finally, as "payment" for voluntarily undertaking the

responsibility of the government. Moving forward, the institution of such a relief will mark the ultimate success of this study.



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## **APPENDIX A: SUGGESTIONS FOR A HIGH QUALITY TAPE RECORDING – PATTON (1990)**

### **I. Equipment**

- a. Use electrical outlet and outside mike whenever possible
- b. If you use batteries check them
- c. Recorder should be clean and in good condition – check before going to an interview
- d. Take along extra tape cassettes

### **II. Before Interview**

- a. Choose a place that's quiet and free from interruptions
- b. Place microphone close to respondent, then speak loud enough so we hear what we are saying; most important we want to hear the answer
- c. Set recorder on stable surface
- d. Test the recording system

### **III. During Interview**

- a. Speak clearly and not too fast – respondent is likely to do the same.
- b. Ask respondent to speak clearly
- c. Make test with respondent: Then rewind and listen so respondent can hear whether he / she is speaking distinctly; if not say, “The recorder does not seem to be picking up well. Could you speak up a little?” Whether the problem is mechanical or personal, correct it before continuing.
- d. Don't rustle papers, cups, bottles and so on near the mike.
- e. Turn off recorder during irrelevant discussion.
- f. Watch for tape breakage and tangling.
- g. Follow all cassette recorder instructions.
- h. At the end of the interview, say “This is the end of interview with \_”

### **IV. After Interview**

- a. Listen to tape – make notes and erase irrelevant discussion (make note of this for transcribers); list proper names and unfamiliar terminology
- b. Label tapes and return them to appropriate containers.
- c. Keep tapes and recorder in good condition – do not touch tape or expose it to extreme temperatures.

## APPENDIX B: INTERVIEW GUIDE

Interviewee: Brother / Sister of \_\_\_\_\_

Interviewed by: Siva Subramanian Nair

Language: English

Location – dd/mm/yyyy

### DEMOGRAPHY

#### STATUS OF DISABLED PERSON

DECEASED

LIVING

AGE

Interviewee

Disabled Person

RACE

RELIGION

#### INCOME BRACKET (MONTHLY)

BELOW RM 2,000

RM 2,000 – RM 5,000

RM 5,000 – RM 10,000

ABOVE RM 10,000

#### NATURE OF DISABILITY

Mental

Physical

## History

*A general description of the disability ...was it from birth or how the person became disabled. Features of the disability etc.*

Do you feel that growing up with a sister / brother with a disability has influenced your life and your character?

*Describe experiences, events...How it has moulded your character, strengthened your will, changed your lifestyle etc.*

Was there a thought of placing her in an institution, home etc.?

*Either way why? is it cost factor, inconvenience, lack of privacy, still able to cope....*

What were the difficult moments?

*Reaction of others, anguish, pain, de-motivation, coping with the disability and bracing yourself at certain times, functions, gatherings etc.*

Do you consider her to be a self-motivator? Do you see her having excelling in life if not for the disability?

*Description of the disabled person's perceptions, aptitude, will power, fortitude, strength of mind & character, grit, determination*

You have stated your religion as a \_\_\_\_\_.

Could your intention to care for your sibling have been motivated by your religious beliefs?

*Did the religious upbringing, the philosophies of religious behaviour, the stories of heaven and hell, the ingrained values, ethics, beliefs, morals, religious principles since young influence you in any way to undertake this caring for or sponsoring of, this disabled sibling*

[If your answer was yes in the last question]

So you feel religion does have an influence in moulding a person's character in terms of caring for the less fortunate.

*A brief explanation/ description of how the influence...*

What was / is the financial status your family ...was money an issue?

*General evaluation such as earnings of parent / (s), contributions from others, expenditure for family, children's education, was there social service support and a general overview of expenditure in respect of the disabled person. [Details of the expenditure should be provided at the end in the Appendix]*

So there is a sacrifice on the part of the siblings

*Description of your sacrifice; time, cost, effort, lost opportunities etc.*

Is there an impact on your own professional work?

***If you were working, how the caring for a disabled person has affected your work, the struggle to maintain good performance, was there any damage to chances for promotions, wasted prospects or breaks at career progress etc.***

What were the costs involved?

***Provide the details in an Appendix***

Our Government has done much for the disabled through its caring society policies.

***Your perception of Government's effort to ensure that the life of a disabled and a normal has minimal variances, has the efforts bore fruit, been of assistance to you in your particular situation....What suggestions can you make?***

Do you feel that the Government should not only concentrate on the incentives for big companies but also look at the small man on the street?

***Where should their priorities lie? On a macro level bringing general prosperity and advancement for the nation or at micro level, thinking of the handicapped, unfortunate, the deprived individual which when addressed will contribute to the whole in line with Schumacher (a philosopher) who wrote "Small is Beautiful"***

What would have been a useful benefit for you?

***What would have been a great help for you? What do you expect from the Government?***

Currently they have numerous reliefs for expenses incurred for supporting a disabled person but it's mainly for the parents, or spouse or children of that person not for the person's brothers and sisters.

***Your view?***

Would a tax relief for your expenses have helped? That means you will be able to deduct the medical costs and other essential items that you had to buy for your sister in relation to her condition against your taxable income; essentially you will pay less tax

***Your view?***

So do you feel a tax relief for siblings would be beneficial?

***Your view?***

In Singapore they have a tax relief for the caregiver of handicapped siblings to the tune of S\$ 3,500 per annum. Do you feel it should be introduced in Malaysia?

***Your view?***