

An Autoethnographic Vignette: The Case of Tax Relief and Sibling Caregivers In Malaysia

Siva Subramanian Nair and S. Susela Devi*

ABSTRACT

Autoethnography is a research approach which uses self-reflection and writing to explore a particular phenomenon but it is seldom used in the business and accounting field. Nevertheless, the autoethnographic approach is not without its benefits and this paper thus advocates using the autoethnographic approach as a way of understanding the trials and tribulations of sibling caregivers of persons with disability. Through this vignette, this paper hopes to highlight the plight of one sibling caregiver. It also emphasises on the anomaly currently existing in the Malaysian tax rules in respect of tax relief for sibling caregivers. By further drawing on the experience of two ASEAN Economic Community (AEC) member countries, namely Singapore and Thailand, this study voices the need to synchronise tax relief conferred on sibling caregivers who are also taxpayers.

Keywords: Autoethnography, ASEAN Economic Community (AEC), Sibling Caregivers, Tax Policy, Tax Relief

JEL Classification: I31, I38, M48

1. Introduction

Autoethnography is a research approach which uses self-reflection and writing to explore a particular phenomenon but using autoethnography in business and accounting research is limited (Davie, 2008; Gibbon, 2012). In this paper, the potentials of autoethnography are explored as a means

*Corresponding author: S. Susela Devi is a Professor at the Faculty of Business Technology and Accounting, Unitar International University, Petaling Jaya, Selangor, Malaysia. Email: susela@unitar.my.

Siva Subramanian Nair is currently pursuing his PhD at the Faculty of Business and Accountancy, University of Malaya, Kuala Lumpur, Malaysia. E-mail: sivasubramaniannair@gmail.com.

to promote empathy and connection (Sparkes, 2002) and it is viewed from the perspective of the first author as a platform to create awareness of the caregivers' plight and trials and tribulation in caring for siblings with disability.

Despite medical care offered by a country, families are increasingly made to bear the responsibility of caring for chronically ill and disabled members (Montgomery, Gonyea, & Hooyman, 1985). The extant literature on caregiving has examined the consequences of caregiving behaviour on the family (Seltzer, Greenberg, Krauss, Gordon, & Judge, 1997; Turcic & Hughes, 2004; Tsao, Davenport, & Schmeige, 2012) and it has made repeated calls for interventions by the government (in terms of fiscal policies and mechanisms) to support such families (Montgomery et al., 1985). Although such interventions may be in the process, there has not been much attention given to the plight of sibling caregivers. This paper proposes reforms which the Malaysian government may be able to take up as a way of providing support to sibling caregivers, for example by extending the tax relief currently given to caregivers of parents, spouse and children.

As nations move towards embracing an aging population, nations also have to make several plans of their own to resolve issues such as long term care of the aged which can be a strain on public resources. Policymakers, for example, may have to seriously consider the family as a resource to mitigate the rising costs of health care. This is an important facet to consider, apart from taxation which is also an avenue for the government to gain necessary resources so as to discharge its accountability to society (Doessel & Williams, 2011).

For decades, the Malaysian government has used the taxation system as a means to provide financial assistance to persons with special needs such as the disabled and their caregivers. To ease the financial burden of the disabled persons, the government has incorporated numerous tax reliefs in its tax legislation. However, the current tax reliefs given to caregivers of persons with disabilities are meant only for their parents, the spouse or their children. No tax relief, credits or incentives are ever given to the individuals who also serve as caregivers of siblings with disabilities. In many cases, siblings are required, through the bonds of love, affection and family ties, to become caregivers in the event of the death or incapacity of the parents to care for the disabled person or when the disabled person himself/herself is unmarried and has no one to care for him/her.

Using autoethnography as a research approach, this paper is presented from the views of the first author who was himself a sibling caregiver looking after a sister with disability. The paper provides an account of the life of the sibling caregiver and the person with the disability. It details the variance between the life of a person caring for a sibling with disability as opposed to that of a sibling in a normal family. The contribution of this paper is threefold: it contributes to current existing literature by illustrating how autoethnography as a research approach can be utilised to raise awareness of social issues; it provides a discussion of tax relief measures in two ASEAN countries; and it suggests that, with the establishment of the ASEAN Economic Community (AEC), the government of Malaysia may need to synchronise the tax relief conferred on taxpayers by extending it to sibling caregivers.

The remaining discussion is organised as follows: Section 2 discusses the need for support for people with disabilities and the role of the government through fiscal policies. Section 3 outlines the current tax reliefs available in Malaysia, and provides a comparison of tax reliefs in Singapore and Thailand. This section also advocates the need to examine the issue of tax relief for caregivers in Malaysia. Section 4 sets out the motivation of this study. Section 5 advances the use of autoethnography, and Section 6 provides an autoethnographic vignette to expose the trials and tribulations of a sibling caregiver. Section 7 discusses the findings and implications thereon, and Section 8 concludes with suggestions for future research.

2. Caregivers Support

Extant literature proposes that support should be given to caregivers to ease the burden of responsibility borne by them. Increasingly, public policies and programmes take account of the change in the demographical contours where the aged are representing a larger proportion and this translates into increased strains of caregiving (Silverstein & Parrott, 2001). Calls have been made for anticipatory measures to be instituted to enable the elderly to care for themselves or through the aid of a caregiver, failing which, the whole burden may be borne by the government (Silverstein & Parrott, 2001).

The British Columbia Law Institute (BCLI) published a study in 2009 entitled "Care/work: Law Reform to Support Family Caregivers to Balance Paid Work and Unpaid Caregiving". It explains how the laws in British Columbia enable caregivers to achieve a balance between their

occupation and discharging their caregiving duties (for which they are not remunerated) and it further evaluates whether or not sufficient recognition is given to this free caregiving services in terms of value to society. BCLI 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.

BCLI (2009) explains that the people taken care of by “family caregivers” include aged parents, disabled children, those suffering from mental disorders, addicts, patients with or who have survived serious diseases such as cancer and persons recovering from surgery. In addition to caring for their own family, these services may be extended to neighbours and acquaintances where they help to administer medicines, keep appointments, help with personal hygiene, provide support with passion, help them to move around, and assist with the work around the house such as cooking, purchasing and other chores, whether on a regular or occasional basis.

For this group of people, caregiving is not a choice because it involves the provision of care with affection. These people do not even think that such services can be fulfilled by employing just anyone. Caregivers of this nature keep a low profile and locating an appropriate candidate is difficult. Further, cost constraint is another restrictive factor, especially in small families where there are too few members to share the financial burden (BCLI, 2009). It has been acknowledged that in Canada the financial strain on the caregivers is mammoth and the inadequate attention to this matter by the government has caused the standard of living of caregivers to recede further (BCLI, 2009). BCLI (2009) explains that the undertaking of caregiving activities is not only an additional disbursement closely associated with the provision of care but that the caregiver is further burdened by limited hours available to them to be employed. This is more so when the care required is extensive. To discuss this further, three key issues are highlighted as follows.

First, the provision of caregiving services, through its adverse impact on the caregiver’s employment, generates a reduction in income. A dilemma ensues, requiring the caregiver to make a decision between whether or not to continue with his/her full-time job as well as caregiving duties even though this burden may have a detrimental effect on the caregiver’s health, or to give up the caregiving responsibility or lastly, to resign from the job. All of these choices have a bearing

on the caregiver's financial constraints, personal me-time as well as socialisation activities.

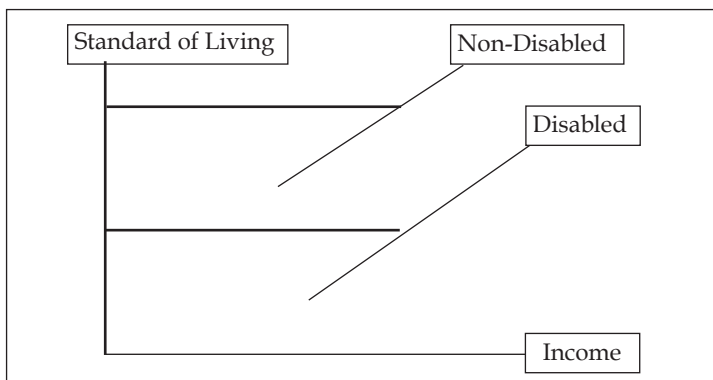
Second, a need arises as to how these caregiving costs can be distributed to associate parties. Besides the caregiver himself/herself, the person being cared for and his/her family, and the employer of the caregiver can culminate to an extent which involves the community at large i.e. it has now become a public issue requiring the attention of policy makers.

Third, three different public policy approaches which can compensate, or provide income support for caregivers are suggested. These encompass a) indirect compensation through tax policy; b) direct compensation through stipends and wages paid to the caregiver through various government programmes; and c) pension initiatives that recognise the labour of caregiving and the long term financial consequences of caregiving on pension security.

This study focuses on the indirect compensation through the tax policy.

2.1 Justice through Taxation

The fundamentals of social justice currently prevailing in modern society have now been extended to and installed as a goal in the field of taxation (Doessel & Williams, 2011). There is recognition that all persons are treated equitably in the administration of tax laws. Such a 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).



Source: Doessel & Willaims (2011, p. 347)

Figure 1: The Relationship Between Income, Standard of Living and Disability

Figure 1 shows that three different and relevant phenomena i.e., the standard of living, income and disability can be conceptually related and depicted visually (Berthoud, 1991, cited in Doessel & Williams, 2011). Although there is no direct relationship between the income and living standards of a person, nevertheless, at all levels of income, the living standard of a person with disability lies below that of an able-bodied person (Doessel & Williams, 2011).

The above discussion serves to demonstrate the concept of “conversion handicap” that is propounded by Sen (2004) which says that by keeping the level of income constant, the disabled person enjoys a standard of living that is below that of an able-bodied person (Doessel & Williams, 2011). As espoused by Doessel and Williams (2011), an alternative way of considering Figure 1 is to ask, “what income does the person with disabilities need to earn in order to enjoy the same standard of living as his/her able-bodied counterpart?” (p. 348).

Assuming that a particular standard of living is necessary, the “income” of a person with disabilities should be supplemented so as to achieve a level that is sufficient to provide him with the required standard of living. Wang, Xu, Shang, and Guo (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” (p. 80).

The importance of equality is examined by Johns and Green (2009) as being a latent nexus between equality and discrimination. They hold that if everyone is treated equally then there is no room for discretion and they contend that the exercise of discretion opens avenues for discrimination to occur. Wang et al. (2010) provide a social perspective of disability where disability is viewed as an exclusion from mainstream society that is experienced by people with impairments and this arises from prejudice and discrimination both at the cultural, social and institutional levels.

To rectify this imbalance and to avoid any profound impact it creates on living standards, Wang et al. (2010) propose that support services and financial assistance be given to persons with disabilities. This notion of equality and justice for the disabled is also extended 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. The undertaking of the responsibility of caregiving whilst also managing his/her own family can obviously result in an enhanced financial burden which translates to a lower standard of living for the caregiver. So, how can this inequity be addressed?

Several avenues are available. However, this study only argues from the perspective of tax in that the taxation system of a nation may provide a reprieve. As the fiscal system is almost always vested in the hands of the government, a review of government policies is thus in order. Government policies can be implemented so as to alleviate inequities of the living standards experienced, specifically, through the disbursement of grants to disabled people (Doessel & Williams, 2011). Increasingly, efforts to assist in shaping policies for disabled people are undertaken by those who generally believe that appropriate policies can be implemented only if there is some positive change in public attitudes toward disabled people (Miles, 2002; Nolan, 2006). Hence, incorporating benefits and reliefs in taxation to facilitate the equitable distribution of income to caregivers, may be an influential consideration for the government to achieve “work-life balance goals” (Nolan, 2006).

2.2 Tax Relief for Caregivers of Persons with Disabilities

Using fiscal incentives as a means of providing financial support to disabled persons is a common government practice in various parts of the world. For example, in the attempt to eradicate child poverty, some governments employ strategies to enhance the rate of employment and to raise the financial support provided to low-income families (Smith, Middleton, Ashton-Brooks, Cox, Dobson, & Reith, 2004; BCLI, 2009; Economic Planning Unit, 2015). However, it is observed that government fundings that can ease the financial burdens of caregivers is still lacking (Silverstein & Parrott, 2001).

Although tax relief by itself would not provide a major reprieve from the financial woes faced by a caregiver, it would, nevertheless, provide some welcome respite. BCLI (2009) explains that tax relief can indirectly compensate the caregiver by lowering his/her taxable income. This helps to smoothen the current cash flow situation. In addition, tax relief also serves as an acknowledgement of caregiving as a valuable service rendered to society, and also to recognise the increasing costs associated with caregiving. Tax policies should look into providing relief for caregivers because in rendering their services, caregivers have less financial resources to allocate for the settlement of their personal tax liabilities. This recommendation is in line with the objectives of the tax policy which, aside from generating revenue for the State, also encourage behaviours that produce economic advantages and benefits to society as a whole. In addition, such an effort can also ensure an equitable distribution of income which provides subsidies to programmes with social values.

Expanding on the above, it appears that tax benefits can be extended to caregivers through the provision of exemptions, tax deductions or even endowing a credit. Any of these can be pursued as a means of providing relief to caregivers for the additional costs borne by them in rendering caregiving services and their personal sacrifices. However, the mode adopted to make this possible must ensure that the benefit reaches the person for whom it is intended. Deductions or credit must be restricted to the quantum of tax payable, and excess of tax paid should be made refundable to the person with disabilities or the caregiver; otherwise, the system loses its significance and becomes worthless.

In line with this argument, this paper focuses first on the tax relief that the Malaysian government has provided for those who need assistance i.e. the aged, disabled and abandoned children. It then compares the situation with its neighbouring countries like Singapore and Thailand who are members of the ASEAN Economic Community (AEC) (MITI, 2014). The purpose is to highlight if the Malaysian tax relief provision is aligned to the regional practices.

3. Current Tax Relief and Incentives In Malaysia, Singapore and Thailand

A comparative summary of the tax reliefs provided in Malaysia, Singapore and Thailand in respect of caring for a disabled person is provided in Table 1. This helps to illustrate who is eligible to claim the relief, what conditions need to be fulfilled and the amount that can be claimed as a tax relief.

3.1 Malaysia

In Malaysia, tax reliefs for persons with disability and their caregivers are contained in the Income Tax Act 1967 (hereinafter referred to as "the Act") and it is basically accorded to a taxpayer as a deduction from his/her total income in ascertaining his/her chargeable income. The tax relief in respect of caregivers is contained in Section 46(1)(c) of the Act entitled "Medical Expenses for Parents".

Initially, Section 46(1) of the Act provided relief only for medical expenses incurred in respect of a parent but it was subsequently revised in 2011 to include special needs of the parent and carers' expenses incurred by the taxpayer for his/her parent. The provision expressly provides that the carer cannot be the taxpayer himself/herself, his/her spouse or child. Other eligibility requirements specify that the parents

Table 1: Carer Relief: A Comparison between Malaysia, Singapore and Thailand

Country	Eligibility to claim	Conditions to claim	Quantum Claimable
Malaysia	Person who incurs medical treatment, special needs or carer expenses for his/her parents	Certification by a medical practitioner who is registered with the Malaysian Medical Council that the medical conditions of the parent require medical treatment or special needs or carer, and the carer shall not include that individual, his wife or her husband or the child of the individual	(Please refer to Table 2)
Singapore	Carer of his/her or his/her spouse's physically or mentally handicapped brothers/sisters who lived in Singapore	No other relief has been claimed on the same disabled sibling who should be living with the claimant in the same household	SGD3,500 for each handicapped brother/sister and to be shared if cared for by more than one sibling.
Thailand	Carer of a disabled or incapacitated family member or non-family member	The claimant must actually support the qualifying disabled person	THB60,000 in respect of each disabled person

*The approximate conversion rates are as follows as at 31 March 2015:
 RM3.7 is equivalent to USD 1
 SGD2.7 is equivalent to USD1
 THB11.4 is equivalent to USD1

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. Nonetheless, the government’s effort to recognise that some individuals have special needs and require the services of a carer is commendable. Overall, tax relief which supports disabled persons in the Malaysian context is summarised in Table 2.

Despite the commendable moves of the Malaysian government, the law provides that tax relief is given only to caregivers of disabled parents, spouses or children. Thus far, there is no tax relief given to taxpayers caring for disabled siblings who through the bond of love, affection and family ties have had to take care of a disabled sibling in the event of death or incapacity of the parents or when the disabled person is himself/herself unmarried and thus has no one to care for him/her.

Table 2: Tax Relief to Support Disabled Persons: A Summary

<i>Disabled Spouse</i> [Section 47(1)(b) and Section 45A]	<i>Basic Supporting Equipment [Section 46(1)(d)]</i>	<i>Disabled Child</i> [Section 48(1)(d) and 48(2)(b)]
<p>An individual can claim spouse relief of RM3,000 in the year of assessment for either 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 RM3,500 may be claimed if the spouse is disabled, for a total claim of RM6,500.</p>	<p>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/her spouse, child or parents.</p>	<p>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 an increased relief of RM6,000. This brings the total claim for a disabled child to RM11,000, with effect from year of assessment 2013.</p> <p>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.</p>

3.2 *Singapore*

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 those individuals supporting their disabled siblings (see Table 1).

In Singapore, tax relief is even extended to any person who has "supported [his] or [her] spouse's physically or mentally handicapped brothers/sisters who lived in Singapore in previous year" (Inland Revenue Authority of Singapore, 2011). The Singapore Tax 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, p. 1). This is illustrated by the following 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". An important condition is that the disabled sibling should "have lived with [the claimant] in the same household in previous year [or] if not, [the claimant] must have incurred SGD2,000 or more in supporting [the disabled sibling] in previous year" (Inland Revenue Authority of Singapore, 2011, p. 1).

Prior to 2010, an additional condition was laid down to explain that the disabled sibling should not have an annual income exceeding SGD2,000 in the previous year, where income includes 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-dependent-related reliefs, the income threshold condition would be removed in recognition of the extra resources and attention needed in providing care to the disabled. Hence, Singaporean taxpayers would be able to claim the reliefs regardless of the income of the handicapped dependent (Shanmugaratnam, 2009).

In terms of quantum, the caregiving sibling is able to claim SGD3,500 for each disabled brother/sister. However, if the same disabled sibling is supported by more than one person the relief of SGD3,500 is shared by all the relevant caregivers.

3.3 *Thailand*

As shown in Table 1, the situation in Thailand is similar to Singapore. Section 47 of the Revenue Code of Thailand "sets out the tax deductible

items . . . for personal income tax calculation purposes” (Suvarnapunya, Nimitkul, & Nishiawatoko, 2009, p.1). 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 supports qualifying disabled persons to take an allowance” (Suvarnapunya et al., 2009). Like Singapore, the relief is extended to any person who takes “care of a disabled or incapacitated family member or care of a disabled or an incapacitated person other than a family member” (PwC, 2011, p. 4) and the amount claimable is THB60,000 in respect of each “disabled person when calculating his/her net taxable personal income” (Suvarnapunya et al., 2009).

Yanagisawaa, Poudel, and Jimba (2010) advocate that government policy has a crucial effect on sibling caregiving. They observe that in many developing countries, communities recognise that their support is not sufficient and that government commitment is necessary. Similarly, Selwyn and Nandy (2011) highlight the fact that welfare policies continue to assume that ‘families’ comprise of parents and children, and fail to consider the large number of children being brought up by relatives.

Additionally, Seltzer et al. (1997, pp. 403-404) feel that “all too often service providers have overlooked the needs of siblings for support and information about the disability”. 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).

To resolve this concern, Seltzer et al. (1997) suggest that the government should include siblings when they take a ‘social inventory’ of individuals who provide regular support to an adult with disabilities. Further, “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” (Seltzer et al., 1997, p. 404).

3.4 Proposal to Review Tax Relief for Caregivers in Malaysia

Malaysia has numerous forms of tax relief for persons with disabilities and it also provides some tax relief for caregivers. However, these are only for the disabled person, the parents, spouse, and children and no relief is available for taxpayers providing care for siblings with disabilities. While the Malaysian government recognises the contributions made by

caregivers, as evidenced by the provision of tax relief to caregivers who are parents, spouses or children of persons with disabilities, it appears to be neglecting the plights of sibling caregivers and this is a disturbing phenomenon to the many sibling caregivers currently sacrificing themselves.

Further, this attitude of the Malaysian government is also perplexing given the government's rhetoric in most of its budgets commencing from the 1992 Budget which indicates that one of the prime objectives of the budget is to create a caring society. In tune with this, it appears that the Eleventh Malaysia Plan (2016 to 2020) also aspires to improve the wellbeing of all *rakyat* (citizens) (Economic Planning Unit, 2015) but what it is doing for now is still in the planning stage. In contrast, it appears that neighbouring countries like Singapore and Thailand have already begun conferring tax reliefs to sibling caregivers. This discrepancy seems to be out of tune with the vision of the country which aims to be a developed nation by 2020. The discussion in Section 2 above supports the need for government and policy makers to give due recognition to the caregiving services provided by siblings.

4. Motivation of this Study

The idea to conduct this study was originally triggered by an inquiry in 2011 which asked if a tax relief was available for money spent on treating and caring for siblings who are disabled. To the best of the first author's knowledge acquired from the many years of practicing and teaching taxation, there was no such tax relief. This gap thus inspired the need to sow the seed of inquiry which culminates into this paper which addresses this inequality.

In the context of this paper, the first author and another sister, as siblings had cared for another sister who was disabled and this caregiving instance was borne out of love and affection without any expectation in return. However, upon recalling the series of events that had transpired during the stage of caregiving, it dawned on the first author that various challenges had been experienced by the siblings while taking care of a disabled person suffering from various disabilities or serious ailment. Recalling on his own experiences as a caregiver, it seems that these various and multi-faceted experiences, traumas, hardships and frustrations endured would be similar to the experiences encountered in the lives of many others who provided caregiving services. Thus, it gave the impetus to develop this study.

Given the nature of the topic, an autoethnographic approach is adopted to unravel and highlight the trials and tribulations experienced by sibling caregivers. As alluded to by Davie (2008, p. 1056), this paper aims to address the need to “speak to an audience ‘out there’ struggling to make sense” of their struggles and experiences in caregiving. In other words, it aims to serve as the voice of the sibling caregivers.

5. Advocating the Autoethnographic Approach

5.1 *What is Autoethnography?*

The autoethnographic approach developed by Ellis (1999, p. 671) explains that autoethnography is “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”.

Reed-Danahay (1997, p. 145), as cited by Doloriert and Sambrook (2011) defines autoethnography as “research (graphy) that connects the personal (auto) to the cultural (ethnos) by placing the self within a social context.” Essentially the method 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 (Ellis, Adams, & Bochner, 2011).

An autoethnographic quest is motivated by the urge to understand one’s self, bridging biography with society, knowledge of the self through a comprehension of one’s life, characteristics and emotions which are related to and form a part of the society and culture in which the researcher co-exists (Anderson, 2006). It gives due recognition to the fact that researchers 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” (Miles, 2002, p. 28).

The use of autoethnography is not something new. It is an emergent practice concerned with writing about one’s own self and identity in the context of organisational studies with a self-narrative that critiques the situatedness of self and others in a social context (Learmouth & Humphreys, 2012; Spry, 2001). Being a qualitative research method, it emphasises a more personal, almost intimate level of study, rendering the researcher-participant opportunities to explore past and present

experiences while gaining self-awareness of his or her interactions and their socio-cultural effects (Butler, 2009).

Autoethnography offers a particular way to situate oneself within the research process and its output by making oneself the object of research and by developing a “reflexive connection between the researcher’s and participants’ lives” (Ellis, 2004, p. 30). Anderson (2006, p. 377) 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, “the autoethnographic label is often deployed in many other contexts and it forms what Richardson and St. Pierre (2005, p. 962) call ‘creative analytical practices’ for example, in various forms of performance ethnography, fiction stories and other less conventional approaches” (Anderson, 2006, p. 377).

As a summary, the comments of Charmaz (2006, p. 397) is adopted and it says “ . . . [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.” In other words, the autoethnography approach can be descriptive, emotional details of particular events which had been written and reflected upon by the person experiencing these events. Thus, no two events recalled may have the same effect on the readers. Furthermore, these narratives could thus be subjectively reviewed. Holt (2003, p. 23) emphasises that the criteria used to judge autoethnography should not “necessarily be the same as traditional criteria used to judge other qualitative research investigation”. Suffice to say that a story can be considered valid “if it evokes in the reader a feeling that the experience is authentic, believable, and possible” (Holt, 2003, p. 22).

This autoethnography approach was adopted for the purpose of this paper. Adopting this approach enables the researcher to relate to the researched phenomena which in this context is the experience of being a sibling caregiver. In addition, the approach enables the researcher to develop an undeniable reflective relationship between the seeker and what is being sought. Such an unison, it is argued, adds authenticity, genuineness and provides a faithful representation of the actual situation or dilemma. The adoption of autoethnography in this study is apt as it aims for a heightened self-reflexivity in this research with a focus on emotion against a postmodern skepticism with regards to the generalisation of knowledge claims (Anderson, 2006). Further, one of

the stimulus motivating this study was the author's frustration with the lackadaisical attitude of the government in giving tax relief to caregivers of disabled siblings.

5.2 Validity and Reliability Issues in Autoethnography

Opinions on the validity and reliability of the autoethnography approach are abundant. According to Lincoln and Guba (1985), the existence of validity also serves to illustrate reliability whereas Patton (2001, p. 300) regards such opinions as "an essential component at the different stages of a qualitative study." However, Stenbacka (2001, p. 552) provides a dissenting opinion by stating that "reliability is founded on measurements and therefore, bears no relevance for a qualitative study." This study echoes Ellis (1999) who suggests validity for this type of research is in the authenticity of the experience narrated and not measurements.

Qualitative studies do not seek to quantify a measurement or to prove that something works or does not work. Instead, qualitative studies are attempts to understand how the world is constructed and in this regard, the world is never viewed by everyone in the same way. Attempts to discredit qualitative studies come in the forms of various criticisms most aiming at their validity constructs (Cho & Trent, 2006) and there are also attempts made to compare them by using quantitative standards (Wall, 2008) with most arguing that qualitative studies lack objectivity, reason and truth (Denzin & Lincoln, 1994, as cited by Wall, 2008). The lack of objectivity prevailing in qualitative studies has been further expounded by Wall (2008) in the following ways: generally in social sciences, the researcher's own values and subjectivities will intervene in his/her research work (quoting Bochner, 2001); 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 these are mainly based on presupposed assumptions and interests (quoting Stivers, 1993). Quoting Thomas (1993), Wall (2008) argues that such studies tend to compromise their scientific values by bowing down to passion, and these tend to come in the form of unsubstantiated assertions which are strident but lacking in reason. These criticisms stem from a lack of understanding of the purpose of autoethnographic research, as well as a need to review reliability and validity criteria from a different standpoint as highlighted by Holt (2003).

Despite these criticisms, there is increasing recognition which notes that autoethnography has a role to play in situating the self-reflections

and lived experiences of an author within a broader hermeneutic endeavor so as to understand the contextual specific meanings of caregiving (Holt, 2003; Humphreys, 2005; Davie, 2008). This study contends that autoethnography involves the experience of the researcher who in turn values narrative truth based on what a story of experience does, and how it is used, understood, and responded to for and by the researcher and as well as readers (Bochner, 1994; Denzin, 1989, as cited in Ellis et al., 2011). In such an approach, the researcher “tells a story that allows readers to enter and feel part of a story that includes emotions and intimate detail and it examines the meaning of human experience.” Such an approach allows readers “to feel the dilemmas and to think with a story rather than about it and to join actively with the author’s decision points” (Ellis & Bochner, 2000, as cited in Wall, 2008, p. 44). It is observed that readers “become co-participants who engage with the story line morally, emotionally, aesthetically, and intellectually” (Richardson, 1994, as cited in Wall, 2008, p. 44). In contrast, it appears that in the world of traditional science, objective distance helps to protect researchers and readers from the emotional and intimate details of human lives (Muncey, 2005, as cited by Wall, 2008). Thus, the authors believe this approach is able to bring out the first author’s own experience in a story with conviction and authenticity.

Acknowledging the fact that the description of an experience will nevertheless contain some minor omissions, Ellis (1999) illustrates that the purpose of autoethnography extends beyond the accuracy of the narratives to an articulation of the contextual experience which displays how the event has affected the researcher, what significance it holds for the researcher and it also describes the implications for him/her and how such a portrayal invites the reader to immerse himself/herself in this very experience. Davie (2008) who likewise also uses autoethnography in her research in accounting reminds us that “[t]here 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” (cited in Thomas, 1993, p. 70).

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. Cho and Trent (2006,

p. 321) support qualitative inquiry from two perspectives: firstly, they question “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?” Secondly, 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.

On the account of reliability, it appears that autoethnography cannot be subjected to the traditional notions of reliability because it represents a narration of one’s personal experiences involving an exercise to bind the present situation with a memory of the past and the anticipated future (Ellis, 1999). Nevertheless, a check for reliability can be performed by allowing a review of the work done for comments or additional information or just as a point of view.

In the present study, the motivation and inspiration to conduct this study arose from the first author’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 prescription offered by Cho and Trent (2006, p. 321) who say that there must be “a progressive, emancipatory process leading toward social change.” This prescription is fulfilled in the current study as it seeks to encourage a review of the tax system by proposing tax relief or rebates for individuals taking care of disabled siblings. In addition, this study also complies with the suggestion by Cho and Trent (2006) to include a critical element to change the existing social condition. In this regard, this paper provides a recommendation to review the current practice of providing tax relief only to spouse, parents and children of persons with disabilities by extending the same relief to sibling caregivers.

6. The Autoethnographic Vignette

The story is that of the first author’s disabled sister who ultimately succumbed to cancer in 2005, and how caring for her had affected his life and the lives of his other siblings. The sister in study was an intelligent and caring person and had always been a bubbling personality with zealous enthusiasm in her ‘normal’ days until a fall condemned her to a life of being a quadriplegic.

In her state of immobility, my sister was provided with a wheelchair but the equipment could not be maneuvered through the rooms due

to its bulkiness and the built-up of the house. Throughout the 40 years of inconvenience, she was however, able to drag herself on her seat throughout the house. The wheelchair enabled her to sit at a table to have her meals. Instead of remaining idle, my sister kept herself busy by helping out with the household chores such as cutting vegetables, sewing (with a modified sewing machine) and caring for her younger siblings such as teaching them, combing their hair, dressing them up and putting them to sleep.

Accepting her fate, my sister continued to live in this condition as she watches her other siblings progress with their lives whilst hers had reached a plateau. Nevertheless, she was an asset to her parents in their twilight years when the other children had left the house after they had pursued their education and became qualified to look for lucrative endeavours of their own. My sister remained with our aging parents and assisted them in many other ways such as attending to telephone calls, giving the necessary insulin injections to their diabetic mother, reading the newspapers for their father when he underwent an eye operation, making garlands for their daily prayers and handling a myriad of unending tasks. The other siblings made sure that sister did not feel useless, and all financial contributions to the family were channeled to her. She literally administered the financial affairs of the family (e.g., settling household bills, grocery shopping, marketing and fulfilling payments to grocers).

My sister's life continued as she served the family in the same manner for 40 years. Even after the demise of our parents in 1995 and 1997 respectively, she continued to bear the responsibilities of "running the family", a role which kept her totally immersed. However, in 2002, when my sister was 56 years old, it was discovered that she was suffering from cancer of the rectum. This medical occurrence entailed a series of operations, nursing care, courses of radiotherapy and chemotherapy which affected her until she finally succumbed to the illness, after three years of agony, pain and suffering.

6.1 The Tribulations Faced by a Sibling

Past events were first recollected based on memories but to make this paper more consistent and valid, the first author continued to meet with his siblings so as to recall the past events of his life by corroborating with the memories of other siblings. To do this, the author initiated fervent discussions with his other siblings which enabled him to identify the trials and tribulations faced by him and the other siblings. These discussions also

allowed him to capture the salient features of the memories including the costs of medications and treatments and psychological factors, physical stress and its impact on the work held by the sibling caregivers.

6.2 The Cost and Psychological Factor

Over the three years of caring for the sister, it was discovered that the total medical cost incurred amount to about RM260,000. Although the siblings have no regrets for spending that amount collectively on their sister since all they had wanted was the best care and comfort for their sister, nevertheless, it was realised that had such an expenditure been spent on a parent or even a spouse or child (since cancer qualifies as a serious disease), the persons spending the money would have qualified for a tax relief of RM5,000 per annum all of which would have amounted to RM15,000 over the three years duration, Likewise, had the same amount been spent on a parent, a child would have been able to offset this amount in his/her tax returns. Unfortunately, no tax relief seems to have been extended to taxpayers who are caring for their disabled siblings.

Although the deducted amount is relatively insignificant, it nevertheless, would serve as a recognition of the individual's contribution as the government appreciates and recognises the contribution made towards caring for a disabled or ailing sibling. Further, such an effort may encourage more individuals to share in their responsibilities when they encounter similar situations.

People living in normal families may not be aware but in a family that co-exists with a disabled person, there are many challenges of living together as the living environment is often one that is complicated and complex. In this case, the author and his siblings were raised in an orthodox Hindu family where the parents were the epitome of piousness and religiosity. Thus, it was difficult to comprehend why such disability befell on a child borne in such a pious family. The general response of the first author's parents (which he now realises had the dual role of also fortifying the relationship between the siblings) was to say that they 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 many took for granted. Once the parents had accepted the child with her disabilities there was no psychological strain experienced whether by the parents or the siblings.

As a matter of fact, our sister proved to be an asset in our family as she not only acquired her tailoring skills but also other talents such

as making beautiful flower garlands. She also developed remarkable aptitude and decision-making capabilities especially when the family had problems and simultaneously, she also had a gift for mediating when conflicts arose between the siblings. As a child, she was never left alone in the house hence, there was always someone around to keep her company whether it was during festivals, family outings, or when visiting relatives. Unfortunately, it was a stressful moment for the person who was required to stay behind as company.

As all good things need to come to an end, so too did my sister's wonderful skills. With the onset of the dreaded illness, her abilities and competencies slowly diminished and she began to question her existence with "This is unfair!", "Why me?" "Haven't I suffered enough?", "There is no equity, no justice, and no fairness!". For my sister, her whole world collapsed; her confidence shattered; her exuberance faded and her mind was oversaturated with a negative attitude. Trying to raise her hopes and positivity took serious cajoling, and lengthy constructive persuasions. Much psychological endeavours had to be embarked upon so as to be able to convince her that there was hope, that she must not give up, that she must fight on and that her siblings were all here to give her support, comfort and security. Another cause which corroded her self confidence also came in the form of others making fun of her or uttering traumatising comments about her disability. Needless to say, as her siblings, these comments also irked us and caused us pain and sufferings.

6.3 The Physical Stress

In looking back, my sister also had her peculiarities during her illness. For example, she was very particular about outsiders carrying her. In the context of the first author who was the older of the siblings, it was natural that he would assume the role of carrying her whenever she was going out (which were rare occasions). Even before the onset of her illness, he would be the one assisting her up and down the stairs and onto the seat of the car. Later, the first author would assist in getting her off from her seat in the car. In the younger days, this chore did not have much impact on him as the first author enjoyed the company of his sister who was able to be out with them in the car. The interaction allowed the author to observe the new developments such as explaining the road changes and traffic flow that had taken place since her last visit out. This seemed like a good experience for all concerned.

However, with the onset of the cancer, my sister's morale had diminished to a low and it seemed to affect her whole being. Moreover, with radiotherapy and chemotherapy treatments, it became necessary for the author to make arrangements to pick her up and send her to the hospital as often as it took for her treatment to be administered. Although the task appeared simple, it was a heavy task for it entailed energy such as carrying her down from the house, putting her into the car, ensuring her safety, driving her to the hospital, assisting her to disembark, running and placing a booking for a wheelchair, placing her into the wheelchair, ensure her comfort and safety and finally lifting her up onto the therapy table. After the treatment session is over, the whole process was repeated in reverse so as to be able to send her home. As mentioned earlier, the task required human energy and lifting and putting an invalid up and down could be an enormous physical strain even on a strong man as the trips were quite frequent (at least four times a week). Moreover, the first author was then also a freelance lecturer teaching and conducting lectures for professional examinations in several colleges in the Klang Valley.

6.4 The Impact on the Sibling's Own Work

The impact of assisting his sister has an effect on the first author's work. Many times while giving lectures, he received messages from home to say that he needed to return home immediately after the lecture because his sister had to be rushed to the hospital. At other times, the author had no means of having his own space of either socialising or interacting with others even when he was not lecturing as someone had to always be with his sister. More often than not, he was usually the one to do so. This affected his preparations for lectures as well as other work-related functions which had to be performed at the hospital at inconvenient moments and spaces. However, the author was often more affected by his sister's physical plight. The sight of seeing her health deteriorate with an uncertain future had a severely debilitating effect on his mind, and this also affected his work performance.

As has been said above, the first author's own experience of being a sibling caregiver is being used in this study to serve as an illustration of the difficulties and problems faced by sibling caregivers with a view to provide a reminder of the role of the State and how it is accountable to society. Living with and taking care of a disabled sibling definitely has tremendous psychological and physical impact on the lives of the

caregiving siblings. At the same time, however, there are also moments saturated with joy and happiness as there are opportunities to show a sibling how much he/she is loved.

7. Discussion

It is clear from extant caregiving literature that government interventions can alleviate inequities in living standards and this can be achieved through the disbursement of grants to disabled people and their caregivers. There is certainly room for improvement in the current state of welfare in the Malaysian context. As proposed in its 1992 budget which aspires to be a caring society, the Malaysian government had introduced many incentives that could help to improve the quality of living and this came in the form of free medical treatment at government hospitals and reserved seats and parking areas for persons with disabilities.

The autoethnographic account applied in this study displays a need to call for tax relief for sibling caregivers not out of greed but rather out of necessity. The recommendation alludes to the reflections narrated as stories of pain and anguish as experienced by the first author. It is deduced that such sufferings and stress may be widespread and shared by other caregivers because the consensus is that "it is better for us to take care of our disabled siblings" than for others who may not know our siblings as well as we do. The above vignette illuminates the experience of one such sibling caregiver who felt it was his responsibility to care for his disabled sister.

The narrations provided here have highlighted the notion that government policies have a crucial effect on sibling caregiving. This is evidenced by the amount of money, time and energy siblings contribute towards the welfare of their disabled siblings. It has been noted that in many developing countries, such support has not been forthcoming for example, statutory support for orphans has not been well-established neither has it been well-functioning. Communities recognise that their support may not be sufficient hence, government commitment is necessary (Yanagisawaa et. al., 2010). There has been limited debate and attention given to sibling caregiver relief and this issue needs to be addressed by many more nations around the region as it affects the individual as well as the society at large. The individual needs to feel recognised for his/her contributions while the society and the government needs to show more empathy for example by considering tax relief for sibling caregivers. The experience of Singapore and

Thailand is worth considering in raising concerns about the Malaysian tax relief anomaly.

Arguably, the State may be considered to be indebted to sibling caregivers for undertaking that role and in this regard, it has a responsibility to assist them in every way possible. One avenue for discharging this responsibility is in the form of the taxation system which could offer tax relief, rebates, incentives and other forms of assistance to such caregivers. The undertaking of the caregiving responsibility has implications in terms of the additional financial burden laid on caregivers. It also has 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 burdens of caregiving.

This paper highlights the experience of a sibling caregiver caring for a person with disabilities. The account raises the awareness that sibling caregivers do undergo tremendous sacrifices and it also alludes to the issue that tax relief may serve to either directly or indirectly alleviate the burden of caregiving. However, the discharge of its accountability through the institution of tax relief for siblings of persons with disabilities should be undertaken effectively. Three distinct questions have clearly emerged from this paper and they are: (1) Who should be the recipient of the tax relief; (2) What is the concept of caregiving as a prerequisite to claim this relief; and: (3) What is the quantum of relief provided? It remains that the answers to the above three questions can only be found via more engagements with sibling caregivers and a heightened dialogue among key policy makers and their constituents.

8. Conclusion

The trials and tribulations faced by the sibling caregiver have emerged as a social issue begging to be addressed and these have gained momentum as a subject for social science research. The use of autoethnography as a research approach has provided this paper with a personal touch to understand the experience of a sibling caregiver and its potential extends to encompass the dimensions of social science research. In this paper, the authors concur with Holt (2003) that if autoethnography is to be justified as a proper research approach, then publication in mainstream journals is a necessary step.

This paper highlights the anomaly in an intervention that was introduced by the Malaysian government to relief the burden of caregivers of persons with disabilities - tax relief for sibling caregivers.

It is not intended to merely make a case to the revenue authorities to institute the relevant tax relief. Instead, it presents a concerted appeal which draws upon the autoethnographic account as a means of convincing the relevant authorities and the government in general, that this call for change is essential because of the following. First, it helps to abate the caregiver's financial burden. Second, it serves as a form of recognition of their services rendered. Third, it serves as a form of compensation for the sacrifices made and finally, it would be an "incentive" for individuals to voluntarily want to undertake the responsibility of the government.

The study contributes to the extant caregiving literature by drawing attention to the role of the State and its accountability to persons with disability, of its responsibility to take care of them and of its assurance of assistance to their families when it delegated this responsibility to them. The families are keeping their part of the bargain by rendering caregiving with love and affection as well as by enduring all difficulties experienced without complaints. Nonetheless, the question arises as to whether the State has effectively and efficaciously discharged its obligations.

This study illuminates an alternative assistance-generating avenue for the State through its fiscal policy. In addition, it is hoped that when the government of Malaysia reviews its taxation policies to synchronise with the tax policies of other AEC members, the government would recognise the gap existing in the tax relief extended to sibling caregivers. Currently, the contribution of sibling caregivers are not recognised in Malaysia thus, they are not given any tax relief, despite playing an important role in providing financial, emotional and physical care and support to disabled siblings.

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