# **CMPH**

Community Medicine and Public Health



## Bulletin

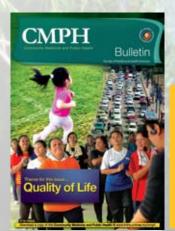
Faculty of Medicine & Health Sciences



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Quality of Life of Mothers of Children with Down Syndrome

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Health and Quality of Life of Persons with Disabilities: **Barriers and Challenge** 

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### FOREWORD BY DEAN, FACULTY OF MEDICINE AND HEALTH SCIENCES, UNIMAS



I am most grateful to the Department of Community Medicine and Public Health for inviting me to give a few words in this second edition of CMPH Bulletin with the theme "Quality of Life".

Quality of Life could be broadly defined as subjective perceptions, feelings, beliefs and values of individual's well-being within the context of different aspects such as economic, social, physical, political, psychological and spiritual.

I am sure that this edition will address the issues of health-related Quality of Life among different subpopulations and provide us with information on the development of individual's perceptions and the current scenario of diseases and its prevention and management.

I hope that this issue of CMPH Bulletin will serve as useful reading and reference for both lecturers and students in the faculty and beyond.

Prof. Dr. Haji Ahmad Hata b Rasit Dean

**Faculty of Medicine and Health Sciences** 



Message from
Assoc Prof Dr Razitasham bt Safii
Head of Department
Department of Community Medicine and Public Health

Welcome again to our second Bulletin with the theme "Quality of Life". This bulletin, a product of the Department of Community Medicine and Public Health, Faculty of Medicine and Health Sciences, UNIMAS, endeavors to become a platform of information sharing of scientific knowledge, best practices, community projects and others. Contributors comprise of not only the faculty members of the Department and Faculty but also its undergraduate and postgraduate students as well as staff from State Health Department and other invited writers.

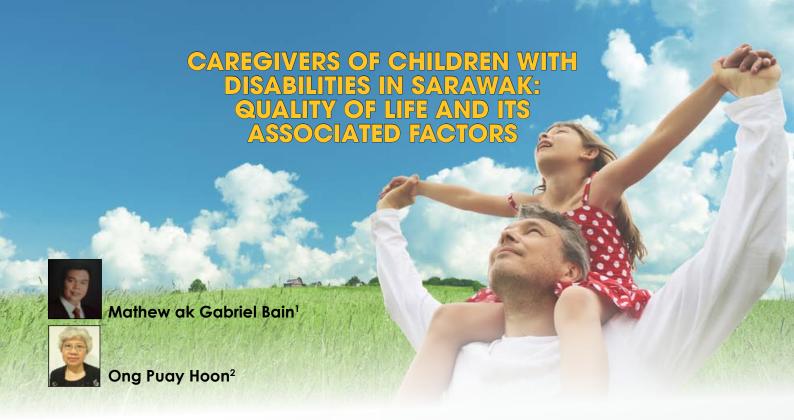
The theme "Quality of Life" is most appropriate towards improvement of health of the population in the 21st century and the realization of a developed status for the country as espoused in Vision 2020. In this bulletin, we have put together showcases of some of the community activities and programmes of the Department, especially in the rural areas. These community-based efforts are integrated within the aims of the Faculty's academic teaching and learning, not only to improve the visibility of UNIMAS especially the Faculty of Medicine and Health Sciences, but more importantly to contribute to the achievement of Health for All and Quality of Life of the communities.

The next issue of CMPH Bulletin (Issue 3) will focus on Rural Health. We invite you to discuss issues related to this theme. Your articles or contributions may take the form of a summary of research output, an anecdotal account of personal experience of service delivery in rural or remote areas, or a critical analysis of any topics or issues related to the theme.

I wish you all happy reading.

X.

Assoc Prof Dr Razitasham bt Safii



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**Keywords:** Quality of Life, Caregivers of Children with Disabilities, Rehabilitation

#### Introduction:

The 2011 World Report on Disability estimates that over a billion people, or about 15% of the world's population, have some form of disability (World Health Organization (WHO), 2011). This has increased from an estimate of 650 million persons with disabilities in 2006 (10% of world population then) and the figure is expected to increase with population growth. The estimated number of children with disabilities under the age of 18 in 2005 was about 150 million (WHO, 2011). However, there is no current reliable estimate on the numbers of children with disability due to limitation of census and surveys to capture childhood disability (WHO, 2012).

The burden of caring and planning for rehabilitation for children with disability will increase due to the imminent population growth and this is expected to add more strain on the current healthcare system of any country. In addition, the tremendous effect on their family members especially on their caregivers cannot be overlooked. The dependency of these disabled children due to their functional deficiency adds to the existing burden among the caregivers that could be detrimental to their own health and livelihood (Lawson et al., 2010). It would also affect

the caregivers' ability to care for their children which in turn will affect the children's rehabilitation progress (Deepthi & Krishnamurthy, 2011).

Many intervention programs have been implemented by both the government and the private sectors in our country, such as the Community Based Rehabilitation programs by the Social Welfare Department and the Ministry of Health, various rehabilitation programs in government clinics and establishment of private rehabilitation centres Non-Governmental by Organizations (NGOs). Despite the development of these services for children with disabilities, there are limited published studies done to evaluate the effectiveness of these programs, relevancy of the programs and achievement of the desired goals. The current focus of intervention programs emphasize on the children and therefore neglecting the unmet needs of their parents or caregivers (Glozman, 2004). This study was aimed to assess the quality of life of the caregivers of children with disabilities in Sarawak, identify their unmet needs and evaluate the effectiveness of rehabilitation services in Sarawak.

#### Methods:

This was a cross sectional study conducted in six divisions in Sarawak targeting Community-Based Rehabilitation Centers (PDK), Public Health Clinic-Based Rehabilitation (CBR) and Non-Governmental Organizations (NGO) Rehabilitation Centers. The participants were chosen randomly among the caregivers of children with disabilities who attended rehabilitation services in these centers. The participants, who had consented to the study, were interviewed face to face using a structured questionnaire adopted from the 'World Health Organization Quality of Life Instrument (WHOQOL-BREF) Questionnaire'.

#### **Results:**

A total of 359 caregivers participated in this study. Among the respondents, 79.4% were mothers, 68.8% were between 30-49 years age group, 90.8% were married, 37.9% were of Iban ethnicity, 51.3% had level of education of SPM (Form 5) and above, 63.2% were housewives, 19.5% had medical illness and 61.8% have two persons taking care of the children. With regards to the socio-demographic categories of their children with disabilities, 28.4% were from the 5-9 years age group, 59.3% were males and 60% have learning disabilities. The mean household income was RM 1.887.63.

Slightly more than half of the respondents (51.8%) perceived their overall quality of life to be moderate and 51% were satisfied with their general health. However, 7% of the respondents perceived their overall quality of life to be poor and very poor while 13% were dissatisfied with their general health, In the domain mean scores, the environment domain scored the lowest among the four domains, with Mean=59.21 (SD=13.31). Further analysis within the environment domain's facets revealed that participation in and opportunities for recreation/ leisure (Mean= 2.78, SD=0.95) and financial resources (Mean= 2.90, SD=0.86) have the lowest mean scores. Multiple linear regression analysis revealed that respondents who were not married (p<0.001), have fewer people to help to care for their disabled children (p<0.01), have co-morbidity (p<0.01) and have female disabled children (p<0.05), perceived a lower quality of life.

#### **Discussion and Conclusion:**

The WHOQOL-BREF domains scores were lower compared to the general population (Hawthorne et al., 2006). In comparison with other studies conducted among parents of disabled children in the Philippines (Gomez & Gomez, 2010) and Hong Kong (Leung & Li-Tsang, 2003), the domain scores in this study were found to be lower than the Filipino parents but higher that the Hong Kong parents. The findings of this study gave a positive reflection on quality of life of the caregivers in Sarawak. The existence of a small group of caregivers who had perceived their own health to be poor/very poor and who were dissatisfied with their general health suggests a need for attention to the health and wellbeing of caregivers as their disabled children are dependent on them. Future strategies should include improving and providing more financial resources and providing more opportunity for leisure activities for the caregivers as these were highlighted to be major areas of concern by the respondents in this study.

The findings of this study have implications to the health authorities in the state and nation to strengthen and create effective and relevant programs to address caregivers' needs, support services and facilities. This study did not include caregivers of disabled children not attending rehabilitation services at the targeted centres and who were bed ridden at home.

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#### QUALITY OF LIFE AND EXPERIENCES OF MOTHERS OF CHILDREN WITH DOWN SYNDROME



Reported by:

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#### **Background:**

Mothering a child with Down syndrome (DS) could be stressful and emotionally overwhelming for some families. The mothers or care-givers were reported to perceive a lower quality of life. Children who are born with this condition are often associated with a variety of developmental delays and various congenital anomalies which require care in the hospital soon after delivery and subsequent medical follow-up. In Malaysia, the Ministry of Health reported an annual figure of more than 600 new cases of children with DS which constitutes almost a quarter of the total number of the children (below 12 years old) with newly reported disabilities (Ministry of Health Malaysia, n.d.). There have been only a few local studies with detailed accounts on children with DS and their parents, particularly in the Borneo state of Sarawak. Therefore, the purpose of this study was to investigate the experiences of mothers caring for a child with DS and their perceived QoL. The main research question which guided the study was 'What are the experiences of Malaysian (Sarawak) mothers caring for their DS child and their QoL?' This paper constitutes part of the main study which highlights some of the concerns faced by these mothers.

#### Methodology:

This study was conducted using a parallel mixedmethod approach within the local ethnic and cultural context in two regions of Sarawak. Experiences of mothering their child were explored using qualitative interviews (N=26) whereas the WHOQOL-BREF instrument (WHOQOL Group, 1996) was used to determine their perceived QoL (N=161). Mothers of children having DS aged 18 years and below were accessed from either schools, Community-Based Rehabilitation centres or child health clinics where their children were attending the interventional or educational programs within and nearby the capital city of Kuching and the rural region of Samarahan Division. Textual data from interview transcripts were managed and analyzed with NVivo 7.0, a computerassisted qualitative data analysis software program. Thematic analysis guided by Creswell's six generic

steps of data analysis was conducted. Quantitative data analysis was done using Statistical Package for Social Sciences 19.0.

#### Findings:

The overall QoL of the respondents (mean=14.0  $\pm$  1.84) was found to be positively correlated with their locality, education, income and marital status with rho (161) = 0.22 to 0.28 (p < 0.01) but inversely correlated with the maternal age, with rho (161) = -0.17 (p < 0.05). Those who had a lower education and income levels, living in the rural locality, older in age and as singles perceived poorer overall QoL. Regression analysis indicates that the combination of these variables together account for 14.5% of the QoL variability (Chan, Abdullah & Ling, 2013).

Two of the major themes which emerged were in terms of their psycho-emotional aspect of their experiences and child-behavior-related care demand. In the context of the psycho-emotional aspect of their experiences, these were related to feeling of shock, confusion, difficult to accept; feeling of shame and guilt which explained why some of the mothers were secretive about their child's condition and shielded their child away from public eye; their feeling of being stigmatized by others; feeling unsupported both emotionally and practically either from their spouses or extended families; various worries about recurrence of DS, child's inability for self-care and future care provisions for their affected child.

Child-behavior-related care demand as another major theme was due to their children's characteristics of tantrum, behaviors that were socially or age-inappropriate or of heightened active level. This was physically exhausting and added to their challenging experiences. However, a wealth of practical knowledge and wisdom could be learnt and emulated from several other mothers who exercised their firmness and competence in setting limits like for any other children.

#### Discussion and implications:

Mothering children with DS in the Sarawak context could be challenging as evident by the mothers' or care-givers' experiences in the psycho-emotional aspect and child behavior-related care. These were partly related to their children's characteristics, familial or societal attitudes. As stated earlier, regression analysis shows that the combination of the mothers' several background variables together account for only 14.5% of the QoL variability. Besides their background variables, familial and societal attitudes, and child characteristics could be possible factors which can impact on the QoL or well-being of mothers.

Resilience model (Van Riper, 2007) emphasizes the need for families to have access to protective factors in term of supports and resources to enable them to cope and adapt to having a child with disability. Care provision should aim to contribute towards a family environment which promotes mothers' QoL and facilitate the optimal development of their child with DS. Insights as gained point to implications for care professionals' practice. These include being anticipative of and sensitive to mothers' initial emotions; imparting relevant information to clear any misconception and unhelpful disability-related cultural belief; facilitating their access to various supports and resources. Health care and social work

professionals' educational preparation would do well to include disability-related element. Besides these, national policy-making needs to be more inclusive in supporting families and children with DS with their future in mind with greater focus to outreach service designed for rural areas.

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# Health and Quality of Life of Persons with Disabilities: Barriers and Challenges



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# Physical Psychological Social Wellbeing Economic Environment

#### **Health and Wellness**

Since 1948, the World Health Organisation (WHO) defines Health as a 'state of complete physical, mental and social well-being and not merely the absence of disease or infirmity' (WHO, 1948). In order to view 'Health' from a positive social-strength perspective, its broader concept as 'well-being' has become a current focus of interest.

In accordance with the broader implication of the WHO's definition of health, Wellness movements promote a holistic understanding of health and wellbeing as an optimum balance across all areas of the human status. In 2006, a number of terms in the WHO Health Promotion Glossary were revised. The term for wellness now reads:

Wellness is the optimal state of health of individuals and groups. There are two focal concerns: the realization of the fullest potential of an individual physically, psychologically, socially, spiritually and economically, and the fulfilment of one's role expectations in the family, community, place of worship, workplace and other settings (Smith et al., 2006).

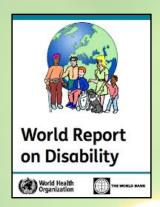
The following diagram by Lunt (2014) reflects the above definition of wellness or well-being as an intersection or a harmonious balance of the different dimensions of living – physical, psychological, economic, environment and social.

This definition postulates that a person is in a state of well-being when s/he

- achieves his/her life's fullest potential physically, psychologically, socially, spiritually and economically, AND
- fulfils his/her life's role expectations in the family, community, place of worship, workplace and other settings.

Despite all the knowledge about health and well-being, and declarations and statements about the rights of all people in societies around the world to attain optimum health and well-being, there remain groups of people that continue to experience inequalities in all the above domains. Persons with disabilities are usually a nation's largest minority and they tend to be marginalised in all aspects of life (Ledman and Brown, 1993). They usually experience substantially poorer quality of life and are more likely to be unemployed due to institutional discrimination. If they do work, they are likely to be underemployed, earn lowsalaries, experience less job security and have fewer chances for advancement (ILO Information Sheet, n.d.).

#### World Report on Disability (WHO, 2011)



The first ever World report on disability, produced jointly by WHO and the World Bank in 2011, suggests that more than a billion people in the world today experience disability. This corresponds to about 15% of the world's population. Between 110-190 million of this group of people have very significant difficulties in functioning. The aim of the report is to support the implementation of the Convention on the Rights of Persons with Disabilities (CRPD) as People with Disabilities (PWDs) have generally poorer health, lower education achievements, fewer economic opportunities and higher rates of poverty than people without disabilities. PWDs are more likely to have poor quality or insecure housing and low levels of workforce participation. This is largely due to the lack of services available to them and the many obstacles they face in their everyday lives, like difficulty accessing transportation and appropriate health care. They encounter barriers of access to optimum health and well-being from service providers, communities and societies that either wittingly or unwittingly exclude or deny them the opportunity to achieve their best health and well-being outcomes.

#### **Health disparities of PWDs**

It is imperative for PWDs to maintain good health to reduce the impact of impairment on functioning and participation. Yet, information from various researches consistently shows that as a group, PWDs experience worse health than the general population (Drum, 2005; U.S. Census Bureau, 2001). Health disparities of PWDs are defined as population-specific differences in health indicators between people with disabilities and those without disabilities (Drum, 2005).

People with physical and cognitive disabilities are more likely to experience early deaths, chronic conditions, and potentially preventable secondary conditions (Lennox et al., 2000; Turk et al., 2001). Furthermore, PWDs report receiving fewer preventive services than the general population (Diab & Johnston, 2004). Adults, adolescents, and children with mental retardation compared with other populations experience poorer health and more difficulty in finding, getting to, and paying for appropriate healthcare (USDHHS, 2002). These differences are underscored by disparities in other areas of wellness including lower rates of high

school completion, higher unemployment, and fewer social activities (USDHHS, 2001).

It is also shown that the information, practices, and resources needed to realize a healthy lifestyle are not available for most people with disabilities (DeJong, 1997). Many health care and service providers do not address health and fitness in people with disabilities. Community resources are still inaccessible for too many people with disabilities, and health promotion campaigns have largely neglected this sub-population. In a recent seminar on public health in Universiti Malaysia Sarawak, a reproductive health program limits itself to the participation of adolescents without disabilities in one school (Gunasegaran, 2014) stating lack of financial and human resources to expand program to adolescents with learning disabilities within the same school. In short, people with disabilities have less access to health promotion and maintenance programs than the general population.

#### Barriers and Challenges to the Quality of Life of PWDs

The following are various barriers and challenges to PWDs as a group in achieving wellness and maintaining their quality of life:

#### 1. Physical Barriers

The public transport in our country, such as Light and Rapid Transit System (LRT), trains and buses, is largely inaccessible to PWDs as many do not have facilities that meet the accessibility requirements of PWDs, although attempts are being made to make them barrier-free and of universal design. Physical barrier in the form of inadequate transportation prevents PWDs from accessing timely and effective health care. PWDs living in remote and rural places experience double disadvantage in regard to receipt of health services, due to issues related to transport and distance, isolation, the nature of service provision (appropriateness, flexibility, co-ordination and location), the need for community and professional disability awareness education, protection of rights, carers and respite ca<mark>re, information dissemination and access to</mark> specialized equipment (Gething, 1997).

The following photographs are some examples of efforts to provide barrier-free travelling for people with physical disabilities in Prague (the first two photos taken by the first author when she was a visiting scholar in Erasmus Mundus Program in Special and Inclusive Education in Charles University, Prague in March-April 2013).



Chair in the lift for people with special needs in Charles University, Prague



A wheelchair lift, Charles University, Prague



A bus with ramp for wheelchairs, Prague
Source: http://www.dpp.cz/en/barrier-free-travel/
buses/

#### 2. Social Barriers

In Malaysia, PWDs have inadequate or no access to basic and advanced vocational training facilities and they lack employment opportunities. Workers with disabilities have been falling behind the general population both in percentage who are full-time employees and in earnings (Hey, 1989) cited in Ledman and Brown, 1993). Employment and a constant source of income ensure everyone, including PWDs, can lead an independent and self-reliant life without overdependence to other people's help. The World Bank in 2000 estimated a total loss to national incomes worldwide between US\$1,370 billion and US\$1,940 billion worldwide due to the exclusion of PWDs from employment opportunities (Khor, 2002). Large federal budget deficits of many countries are reduced in two ways when PWDs are gainfully employed - the

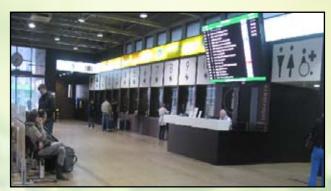
newly employed no longer receive government payments and they pay taxes. The same article estimated loss to Malaysia's national income at between US\$1.18 billion and US\$1.68 billion.

Employment is an important element in everyone's life, including PWDs. Employment and work provide individuals with a sense of participation, social status and a sense of identity. For persons with disabilities, employment also plays an important part in alleviating poverty. An over-dependence of caregivers and a welfare state combined with the lack of employment opportunities for PWDs could create a social milieu where they do not have chance to fully develop their potential.

In recognizing that employment is an important determinant to the quality of life of PWDs, the Malaysian government has announced that at least 1% of the job opportunities in the public sector will be allocated for people with disabilities since 1988 (Public Service Department of Malaysia, 2008). In 1990, the private sector was encouraged to follow suit. However, various researches have shown that the target in civil service is far from being achieved (Furuoka et al., 2011, Tiun et al., 2011).

In an attempt to provide PWDs with an equal chance of employability, a non-government organization, Beautiful Gate Foundation for the Disabled partners with Japan International Cooperation Agency (JICA), SIFE Tunku Abdul Rahman College and Say IT Sdn Bhd to create a website to link employers with disabled persons called okujobs (website address: http://okujobs.com.my/).

The photographs below show the employment of people with vision impairment in Prague.



An employee with vision impairment (partial blindness) manning the information counter at the Florenc bus station, Prague



A man with complete blindness employed by Tesco supermarket to give away free promotional materials in Narodni Trida, Prague

#### 3. Attitudinal Barriers

PWDs were often seen as a "burden" by their families and Malaysian society in the past, resulting in many of them confining themselves to their homes and limiting their daily outdoor activities. Many suffered discrimination due to society's prejudice, ignorance and negative attitudes. Although such mentality has changed in recent years allowing more PWDs to become more independent, there are still public prejudices and misconceptions about employing PWDs and discriminatory attitudes among employers (Schur et al., 2009) and healthcare staff (Thornicroft et al., 2007, Michael, 2008).

#### 4. Institutional & Legislative Barriers

Malaysia has pledged its commitment to improve the lives of PWDs by participating in or becoming a signatory (party) to several regional and internationalinstruments or agenda such as United Nations Charter (1945), Universal Declaration of Human Rights (1948), UN International Year of Disabled Persons (1981), UN Decade of Disabled Persons (1983-1992), Convention on Rights of the Child (1989), Proclamation on the Full Participation and Equality of PWDs in the Asia and the Pacific (1994), Decade of Disabled Persons for Asia and Pacific (1993-2012), Biwako Millennium Framework for Action (2003-2012) – Towards an inclusive, barrier-free and rights-based society for PWDs and the UN Convention on the Rights of Persons with Disabilities (2006).

However, to this day, PWDs in Malaysia are still being excluded and marginalized as a result of physical, social and attitudinal barriers. PWDs are greatly disadvantaged by the lack of national policies and legislation needed to create an environment that would bring about their empowerment in terms of equal opportunities and full meaningful participation in society which will give them wellness in their lives.

#### **Promoting rights for PWDs**

In the past, people with disabilities were considered objects of charity or people in need of welfare and medical interventions, rather than equal members of society entitled to the same rights and privileges as others. Today, however, the understanding of disability is based on what is called the social model, which recognizes that the disadvantages and barriers that disabled people face are largely the result of the social and physical environment. The social model suggests policy approaches based on human rights, integration, inclusion, universal design, and antidiscrimination measures. It holds to the premise that people with disabilities are entitled to the same rights as other human beings.

The United Nations has endorsed the rights of disabled persons to full participation in several instruments, notably the Convention on the Rights of Persons with Disabilities (CRPD) which came into force on 4 April 2008. It is a major milestone in the promotion of equality for people with disabilities (UN Enable, n.d.).

At the national level, most countries have some form of legislation to safeguard the rights or promote employment opportunities for disabled persons. Often, employment promotion measures take the form of quota systems, with levies assigned to employers who do not comply with the required quota, or of antidiscrimination measures with requirements for reasonable accommodation. Many countries also have hiring incentives, promotional schemes, technical supports or other measures to promote the employment and retention of workers with disabilities (International Labour Organization, n.d.).

The first comprehensive legislation on disability in Malaysia is The Persons with Disabilities (PWDs) Act 2008 (Act 685). This legislation reflects the philosophy of the UN CRPD by taking disability as an issue of rights and equality. It states that disabled people should be treated equally with access to public services and facilities, and that the government and pertinent providers should make necessary improvements in ensuring availability to services for the disabled. However, this is not an anti-discrimination law such as the American with Disability Act 1990, and does not contain punitive clause within this act itself.

#### Conclusion

A person with a disability is at a substantially higher risk for experiencing poorer health status than the general population. This disparity appears related to differences in access to medical care and to health promotion services. Eliminating this disparity requires changes in access to medical care, improvements in the delivery of health promotion, increased prevention strategies and removal of physical, social, attitudinal, institutional and legislative barriers.

Everyone, including PWDs, has the right to a good quality of their lives. The need to facilitate the social and emotional well-being of PWDs in terms of their rights for healthy and safe relationships, home and family, nurture and love, freedom and peace, pleasurable life experiences and leisure and their physical and environment wellbeing in terms of their rights for access to physical needs such as adequate food, water, clothing, secure place to live, regular exercise, transport, access to medical care, recreation and pleasurable occupation has become very important and must receive greater attention. With the increase in population growth in Malaysia, the proportion of persons experiencing disabilities will concomitantly increase. Public health has a significant role to play in addressing and ameliorating the health disparities experienced by people with disabilities.

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# My Summer Studying in Malaysia

Reported by:

#### Sheila Alagemand

Master candidate, University of South Florida United States of America

I am currently a student at the University of South Florida (USF), pursuing a Masters of Public Health with a focus in global communicable disease. I got the opportunity to travel to Kuching, Sarawak this past summer to help continue my education in Public Health. One of the requirements for USF's Masters program is completing a field experience, where students get to apply their classroom knowledge in practice, as well as gain experience in the field of Public Health. I chose to do an international field experience (IFE) in Malaysia because I felt it would not easily find in the United States.

Before I left for Malaysia, I set a few goals for myself to achieve while I was there. These included:

- 1. To learn about different perspectives on Public Health in the Malaysian culture.
- 2. To become familiar with different cultural practices, and how they affect the overall community health.
- 3. To understand and apply different disease control practices on the infectious diseases endemic in South East Asia.
- 4. To gain hands-on experience with Public Health in a real world setting.
- 5. To gain a global perspective on different disease control strategies.

Every day when I went into work, I learned a new skill regarding surveillance and control of communicable diseases. I learned about the overall surveillance process for all the major communicable diseases that are important in Sarawak. I also got to see how diseases are reported through the computerized surveillance programs, namely e-notifikasi and e-wabak. Not only did I see the health/vector labs in Kuching, I also got the opportunity to travel to different sites where the communicable diseases are infecting people, to learn how to prevent them from occurring. I found it amazing how during an outbreak in a rural community, many health officials would volunteer their time to go to the site to help treat the patients and promote awareness on how to prevent the disease from occurring.

Ilearned about the Malaysian health care system and how they provide services to the people. I travelled to different health care clinics throughout Sarawak and talked to the officials responsible for providing the services. I got the chance to work at each level of the health care system from the district to divisional to the headquarters. I learned about specific roles unique to each level and how they all work together to improve the health of the people living in the state.

By doing my IFE in Kuching, and interning with different Public Health officials, I was able to obtain a unique working experience that would be difficult to acquire in the US. This experience has helped me learn about many new diseases that are endemic in Sarawak that we do not worry about in the US such as Japanese Encephalitis. Living in Sarawak taught me the importance of proper surveillance and how data collection can be used to help eliminate diseases in a community. I learned that treating any type of endemic diseases is a team effort that can fail without collaboration and help from the community. I also learned the importance of researching the community and understanding cultural practices in different ethnic groups if you want to implement a successful prevention/treatment plan. The trip taught me that educating the community is one of the best investments you can make as a Public Health practitioner to ensure the success of your program. This is seen everyday how Sarawak is able to successfully give people in rural communities access to health care.

Thank you to my amazing supervisor Dr. Razitasham and her wonderful team. Because of them, my experience went above and beyond any expectations I had before I arrived in Sarawak. This trip reinforced my passion for Public Health and I am excited to practice everything I have learned. I will soon graduate from the University of South Florida with my masters and I hope I will get the chance to come back to Malaysia to give back to the country and people that has taught me so much.



Malaria lab, DHO Kuching



Tuberculosis control team, ATAS Clinic



# BIG DATA CHALLENGE BY MINISTRY OF MULTIMEDIA & COMMUNICATION, MDEC & TENTSPARK

**CO-ORGANIZERS: IBM and MICROSOFT** 



#### **MOH-UNIMAS-TERADA-MMU TEAM**

Left to right

- 1-3 Students from Malaysia Multimedia University (MMU)
- 4 Prof CY TING, Faculty of Computer Science, MMU
- 5 Dr Dhesi Baha Raja, Ministry of Health Malaysia cum Doctoral candidate, Faculty of Medicine & Health Sciences, UNIMAS
- 6 Dr Peter Ho, Deputy Dean, Faculty of Computer Science, MMU
- 7 Mr. Craig Morisson, Data Scientist, TERADATA
- 8 Mr. Szilard Barany, Data Scientist, TERADATA



Report Prepared by:

DR DHESI BAHA RAJA

Doctoral Candidate

Doctor of Public Health Programme

Department of Community Medicine and Public Health
Faculty of Medicine and Health Sciences

UNIMAS

#### INTRODUCTION:

BIG DATA is an all-encompassing term for any collection of data sets so large and complex that it becomes difficult to process them using traditional data processing applications. The challenges include analysis, capture, curation, search, sharing, storage, transfer, visualization, and privacy violations. The trend to larger data sets is due to the additional information derivable from analysis of a single large set of related data, as compared to separate smaller sets with the same total amount of data, allowing correlations to be found to "spot business trends, prevent diseases, combat crime and so on.

#### DR DHESI BAHA RAJA (MOH-UNIMAS REPRESENTATIVE):

Dr Dhesi Baha Raja is from Ministry of Health, and is currently pursuing his studies in Unimas. During his service in MOH, he has developed many health informatics programs such as I-Kelahiran, I-Daftar and won two national innovation competitions. He has just completed his Master in Public Health and is currently pursuing his Doctorate studies in UNIMAS.

#### **BIG DATA COMPETITION:**

The Big Data Competition was held to identify and nurture young talented Malaysian in order to curb the recent dengue issue. More than 100 teams joined the competition organized by Ministry of Multimedia & Communication, MDEC, TENTSPARK, IBM & Microsoft.

MOH-UNIMAS-TERADATA-MMU was shortlisted at the top 10 in Malaysia during the first round and was selected to enter the finals. With good teamwork and commitment, we won the competition in Malaysia.

#### **OUR IDEA, OUR CONCEPT:**

In order to win the competition, we had to take a different approach. Dengue data and meteorological data were provided to us. Now it is up to us to execute and win this battle.

#### **DENGUE INDEX MODEL (Dengue Outbreak Predictor):**



Correlations between dengue outbreaks and meteorological events are well known. However, these correlations remain as rule-of-thumb ('rainfall' -> 'dengue'), or as complex models which are not communicated well to the public.

There is a need for a central reference point which will alert the general public on the predicted danger of a dengue outbreak in their locale.

We aimed to develop a solution that can on one hand inform and educate the people on the current level of dengue threat and guide them to the right prevention steps, and on the other hand help the government to optimize the use of the vector control measures and improve the efficiency of prevention.

Therefore, The MOH UNIMAS Teradata MMU Team worked together to understand the factors that lead to dengue outbreaks and develop an index to forewarn communities, medical practitioners and authorities

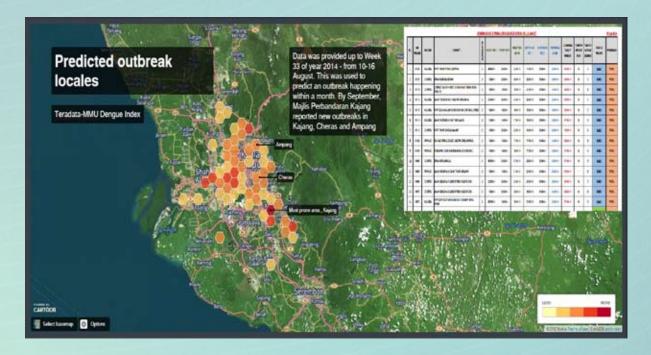
#### The Dengue Index

- An application that predicts the likely occurrence of dengue outbreak
- Based on advanced analytics of weather, construction, dengue statistics and other data to produce an index for each locale in Malaysia

#### **Complex Model:**

The target key outcomes:

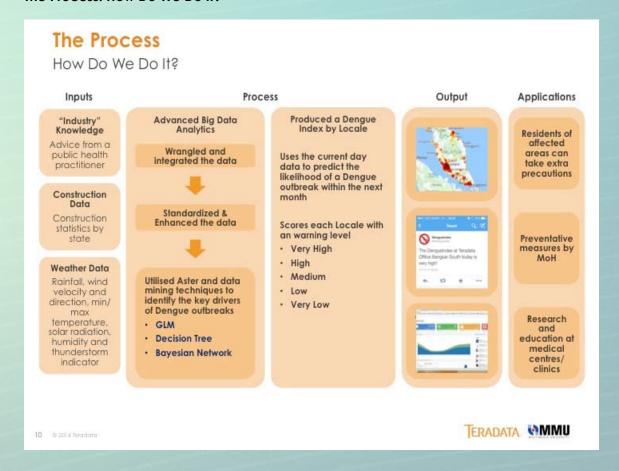
- Web app incorporating Decision Support System and Dengue Index
- Standalone app
- Predictive models using Decision Tree and Bayesian Network
- Empirical proof of predictive model



#### Inputs:

- Weather Data
  - Rainfall, wind velocity and direction, min/max temperature, solar radiation, humidity and thunderstorm indicator
- Construction Data
  - Quarterly construction statistics by state for the last 5 years
- Atmospheric Data
  - Country level data
- Survey Data
  - Altitude data

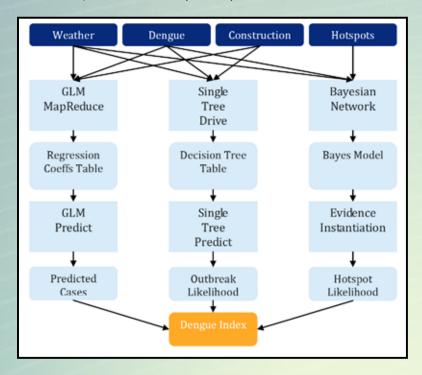
#### The Process: How Do We Do It?



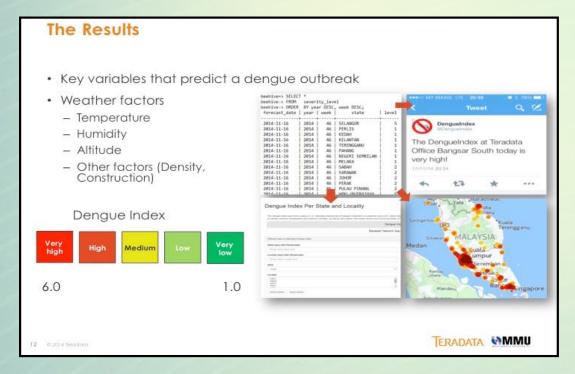
#### **Analytics Method:**

We utilized a combination of statistical analytics techniques and new advanced big data analytics techniques to identify the key variables that affect Dengue incidence such as:

- GLM (Aster)
- Decision Tree (Aster/Weka)
- Bayesian Network (GeNie)



#### **RESULTS:**



#### **CONCLUSION:**

MOH-UNIMAS-TERADATA-MMU team was the first time to create such a predictive model. We hope with this new innovation, the health authorities and the community will be able to identify high risks areas, and be prepared for future outbreaks. This will allow the health authority to intervene at an early stage and mobilize their expertise towards a more proactive approach rather than a reactive approach.

## LAUNCHING CEREMONY OF FAMILY HEALTH COURSE FOR YEAR 1 MEDICAL STUDENTS IN KAMPUNG PASIR PANDAK, KUCHING



Reported by:

Faridah bt Mohamed

Community Development Officer
Faculty of Medicine and Health
Sciences

The Official Launching Ceremony of Family Health Course (MDP 10602) Session 2014/2015 was held on Saturday, 18 October 2014. It was officiated by YB Dr. Haji Abdul Rahman bin Haji Junaidi, Member of State Assembly (N4), Pantai Damai at Dewan Desa Wawasan, Kampung Pasir Pandak. The handing-over of the students to their respective foster parents was successfully done and was witnessed by the Assoc. Prof. Dr Hj Mohammad Ibrahim Safawi (Assistant Vice-Chancellor, UNIMAS), Prof. Dr Haji Ahmad Hata Rasit (Dean, Faculty of Medicine and Health Sciences, UNIMAS), Assoc. Prof. Dr Kamarudin Hj Kana (Deputy Dean) and senior staff of the Faculty of Medicine and Health Sciences and other invited guests.









Family Health Course is compulsory for the Year 1 and Year 2 students to get some hands-on experience through an adoption programme with the villagers of Kampung Pasir Pandak and Kampung Pasir Panjang. The students will visit the village about nine times during the programme for various teaching and learning activities with their foster families. At the end of this course, students should be able to describe the structure, role and function of the family and its members, describe the patterns of family interaction, identify various resources in the family, describe the family lifestyle, family health behaviour and factors affecting health behavior, identify and discuss various problems and factors affecting the family health, identify and discuss the family coping mechanisms in health and ill health including in terminally ill patients, identify the health status of the family in term of their nutritional aspects, immunization, family spacing and other preventive measures and describe the importance of managing problems through preventive and promotion activities.







Activities conducted include health screening and exhibition







Students with new foster families







#### Health status of elderly in KAMPUNG DATU, KAMPUNG BANDONG AND KAMPUNG ABANG BARIENG, SIBU



Reported by:
Cheu Teck Ceng
Year 4 Medical Student
Faculty of Medicine and Health
Sciences
Universiti Malaysia Sarawak

#### Introduction

The number of those in the ageing population is increasing in almost every country worldwide, including Malaysia. This has substantial implications on a family's social structure, the nation's labour force and government spending. With this in mind, 31 students of Universiti Malaysia Sarawak (UNIMAS), who were posted in Sibu under the Community Medicine and Public Health (CMPH) posting, decided to conduct a study on the general health status of elderly aged 60 years and above in Kampung Datu, Kampung Datu Baru, Kampung Bandong, and Kampung Abang Barieng, Sibu.

The main objectives were to determine

- the health status of elderly persons in these kampongs,
- their self-health perception, and
- the association of health problems with their socio-demographic factors.

#### Methodology

A cross-sectional study design was used, with four villages selected for the study, namely Kampung Datu, Kampung Datu Baru, Kampung Bandong, and Kampung Abang Barieng, Sibu. Data was collected from the 13th of October 2014 to 24th of October 2014. A total of 125 out of 230 elderly (response rate of 54.3%) were included in the study, taken via purposive sampling. Data was collected using an interviewerguided questionnaire, which was adapted from the Elderly Health Status Screening Instrument (EHSSI) of the Ministry of Health Malaysia. Approval was obtained from the Department of Community Medicine and Public Health, Faculty of Medicine and Health Sciences, UNIMAS and the Sibu Divisional Health Office. Informed consent was obtained from the respondents.

#### Results

The mean age of the respondents was  $70.7 \pm 8.04$  years. Females constituted 66.4% of the respondents, with more than two third of the respondents with education of at least primary school level. Almost all of them (98.0%) were living together with their family members.

A majority (75.2%) of the respondents had moderate to good self-perception towards health. The most common chronic illnesses among the respondents were joint pain (67.2%), followed by hypertension (64.8%), disability (42.4%), diabetes (29.6%) and asthma (13.6%). Majority of them (80.8%) had two or more chronic illnesses. Regarding their current health status, 12.8% of them complained changes in urination, and about 10% of the respondents had prolonged cough or hoarseness of voice. The prevalence of oral health status such as wearing dentures and gum problems were 61.6% and 20.0% respectively. The prevalence of risk factors of unhealthy diet, physically inactivity, and falling risk, were 56.8%, 63.2%, and 51.2% respectively. Mental health problems, specifically the risk of getting dementia, had a prevalence of 38.4%. Regarding biometric risk factors for 93 respondents, 65.6% of them were hypertensive, 70.7% had abnormal waisthip ratio, and 68.9% were overweight and obese.

In terms of association, occupation had a significant relationship with healthy diet (p<0.05), while smoking was significantly associated with gender (p<0.005) and with occupation (p<0.005). There were no other significant associations between socio-demographic factors with comorbidities, risk factors, and mental health.

#### Conclusion

Generally, the health status of the respondents were good, even though majority of them had two or more chronic illnesses and practiced unhealthy lifestyle such as unhealthy diet, being physically inactive, and had risk of falling. Thus, they should be educated on healthy lifestyle behaviours, such as low-impact aerobic exercise. Collaboration between the public health department and non-government organisations (NGOs) are needed to promote elderly health among them.

#### Side-notes:

An intervention programme, which included a health exhibition, aerobic exercise, health screening, eye and dental check-up, medical consultation and physiotherapy sessions, was held. Out of the total of 69 people of various age groups who were screened, two persons were suspected to have hypertension and was referred for further investigations; 22 participants had high cholesterol reading and 29 participants had high random blood capillary glucose. In addition, a gotong-royong session at the village's Al-Jannah Surau, Kampung Datu Baru was carried out on 26 October 2014.

An appreciation dinner was held for the 31 students posted in CMPH posting, Rotation 2 2014/2015 session. It was held on 11th October 2014 at RH Hotel, Sibu. This event was fully sponsored by the representatives from JKK Kampung Datu Baru, Sibu. Various activities were held, such as karaoke singing among the villagers, dance performance by students of UNIMAS, duet by two students of UNIMAS, "poco-poco", and lucky draws. Overall, it was a fun and enjoyable night. We deeply expressed our gratitude and appreciation towards their cooperation during the research and health intervention day, which not only ensured the success of the activities, but also provided a conducive environment towards our welfare.



Group photo with the villagers of Kampung Datu Lama, Sibu





Gotong royong Al-Jannah Surau, Kampung Datu Baru



Aerobic exercise



Screening for random blood glucose and cholesterol



Medical Consultation with a Medical Officer from the Divisional Health Office



Eye screening for cataract and glaucoma



Dental health screening





Demonstration on exercise techniques by physiotherapists from Sibu Hospital



Pharmacists from Sibu Medical Store held a health exhibition and health talk regarding types of medication and how to recognize fake medication



Health exhibition



Group photo after the closing ceremony



Group photo with JKKK members of Kampung Datu Baru, members of the Pusat Aktiviti Warga Emas, Assoc. Prof. Dr Razitasham Safii, Head of Community Medicine and Public Health Department and health personnel from Oya Health Clinic, Sibu

## BORDER AND DEVELOPMENT INTERNATIONAL CONFERENCE 2014,

5-7<sup>TH</sup> NOVEMBER 2014, FACULTY OF ECONOMY, TANJUNGPURA UNIVERSITY, WEST KALIMANTAN, INDONESIA



Reported by:

Haseanti bt Hussein

Doctoral candidate

Doctor of Public Health Programme

Department of Community Medicine and Public Health
Faculty of Medicine and Health Sciences, UNIMAS



Left- Right:
Dr Nanthakumar Thirunavukarasu, Dr Nor Zam Azihan Hassan, Assoc Prof Dr Md Mizanur Rahman, Dr Deburra
Peak Ngadan, Dr Eunice Melissa Joseph, Dr Haseanti Hussein

The DrPH final year students participated in the Border and Development International Conference (BDIC) in Universitas Tanjungpura, Pontianak, Indonesia held on 5-7 November, 2014 led by Assoc Prof Dr Md Mizanur Rahman. The UNIMAS DrPH delegates presented a total of five scientific papers in the international conference, which was attended by participants from Malaysia, Japan, Bangladesh and host country, Indonesia. The students took the opportunity to present their preliminary findings from their research. It was a useful platform for the students to practise their presentation skills before an international audience, exchange research ideas and build friendship and network with other university students, lecturers and researchers. Several areas for research related to tobacco and smoking were identified such as border trade of tobacco and the implementation of tobacco control regulation at the borders, among others. The following is a list of papers presented by the DrPH students and Assoc Prof Dr Md Mizanur Rahman:

- "Perceived Health Related Knowledge, Attitude, Pictorial Warnings And Quitting Attempt To Smoking Among The Adult Population In Sarawak, Malaysia" (Assoc Prof Dr Md Mizanur Rahman)
- "Sociodemographic Characteristics Of Patients Attending Health Clinics In Sarawak"
   (Dr Nor Zam Azihan bin Hassan)
- "Factors Affecting Equity In Healthcare Service Among The Suburban And Rural Population In Sarawak" (Dr Eunice Melissa Joseph)
- "Determinants Of Utilization And Level Of Satisfaction Of Antenatal Services In Sarawak" (Dr Deburra Peak Ngadan)
- "Prevalence Of Backpain Among Pam Oil Workers In SALCRA" (Dr Nanthakumar A/L Thirunavukarasu)

#### EDUCATIONAL VISIT TO WEST KALIMANTAN PROVINCIAL HEALTH DEPARTMENT, INDONESIA



Report prepared by **Deburra P. Ngadan**Doctoral candidate

Doctor of Public Health

Programme

Department of Community Medicine and Public Health

Faculty of Medicine and Health Sciences UNIMAS

On the 4<sup>th</sup> November 2014, the final-year students of Doctor of Public Health (DrPH) programme visited the West Kalimantan Provincial Health Department, Indonesia. They were accompanied by Assoc. Prof. Dr Kamaluddin Bakar and Assoc. Prof. Dr Md Mizanur Rahman. The visit aimed to expose the students to a non-Malaysian setting of healthcare delivery management and system in both the clinical and public health aspects and to strengthen the interborder ties between UNIMAS and West Kalimantan Provincial Health Department. The group was received by Mr Antonius Suprayogi (Epidemiologist) and Madam Nunung Joeniartin (Secretary). The students



Left- Right:

Assoc Prof Dr Kamaluddin Bakar, Dr Nanthakumar Thirunavukarasu, Dr Nor Zam Azihan Hassan, Assoc Prof Dr Md Mizanur Rahman, Dr Haseanti Hussein, Dr Eunice Melissa Joseph, Dr Deburra Peak Ngadan, Mr Antonius Suprayogi

were briefed on the organizational structure followed by a discussion on health care management and health delivery system of both countries. Important public health issues related to the "Tobacco Control Program", "Malaria Control Program", "HIV & AIDS Control Program" and Ebola preparedness were also discussed. The public health challenges of advocating the current policy were touched upon too. The group then visited PUSKESMAS Kampung Bali, a health centre in Kota Pontianak to observe the primary health care service activities. The visit's objectives were met and the students were able to appreciate the similarities and differences between the Indonesian and Malaysian health care setting. The visit was an enlightening experience.

#### EDUCATIONAL VISIT TO FACULTY OF MEDICINE, UNIVERSITAS TANJUNGPURA, PONTIANAK, INDONESIA



Reported by **Deburra P. Ngadan**Doctoral candidate

Doctor of Public Health

Programme

Department of Community Medicine and Public Health

Faculty of Medicine and Health Sciences UNIMAS

The final-year students of the Doctor of Public Health (DrPH) programme visited the Faculty of Medicine, Universitas Tanjungpura (UNTAN), Pontianak, Indonesia on 4th November 2014, accompanied by Assoc. Prof. Dr Kamaluddin Bakar and Assoc. Prof. Dr Md Mizanur Rahman. The group was welcomed by Dr. Bambang Sri Nugroho, Dean and Dr. Arif Wicaksono, Deputy Dean I. The main purpose of the visit was to strengthen the relationship between the Faculty of Medicine and Health Sciences, UNIMAS

and the Faculty of Medicine, UNTAN. The students were briefed on the different courses offered in the faculty, the faculty's management structure and the learning system employed. A discussion was made on how the two universities can and help to improve the doctor-patient ratio especially in the regions near the border. At the end of the session, a token of appreciation was given to the Dean and a group photo was taken in front of the faculty's building. The objectives were met and it was a memorable experience for all those involved.



Left- Right:

Dr Haseanti Hussein, Assoc Prof Dr Md Mizanur Rahman, Assoc Prof Dr Kamaluddin Bakar, Dr Deburra P Ngadan, Dr. Bambang Sri Nugroho (Dean), Dr. Arif Wicaksono (Deputy Dean I), Dr Eunice M Joseph, Dr Nanthakumar Thirunavukarasu and Dr Nor Zam Azihan Hassan.

