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Obesity is a “multisystemic disease in disguise” that has risen to epidemic proportion in the last few decades. Malaysia is rated the highest in obesity among the Asian countries with a rate of 45.3%\(^1\). Nevertheless, many physicians disregard it as a disease but rather a risk factor or complication. This perception risks failure to manage obesity effectively in a holistic manner and by a multidisciplinary team, ideally consisting of physicians, dieticians, physiotherapists, bariatric surgeons, and mental health professionals. Volkow and O’Brien (2007)\(^2\) proposed to consider that obesity a brain disorder. This underscores the idea that psychiatrists may have greater role in tackling obesity than currently perceived.

Interestingly, psychiatric disorders particularly depression, together with obesity are common non communicable diseases with complex interaction. Substantial psychopathology may exist in obese individuals; particularly mood and anxiety disorders, eating disorders like binge-eating and addiction problems. The risk of weight gain and obesity in those with major psychiatric disorders is high\(^3\) and vice versa\(^4\); as observed locally as well\(^5\)\(^7\). Often the cause and consequence among these disorders become indistinct but they intermingled. Regardless, underlying psychological factors influencing obesity need to be addressed as these posed obstacles to successful weight management. Moreover, the use of psychotropics that contribute to weight gain have to be identified and minimized.

Psychiatric assessment of an obese patient is aimed at identifying and assessing the severity of psychopathology, psychological traits, psychosocial issues and maladaptive coping mechanisms that promotes eating behaviour and subsequent weight gain. These ranged from underlying low self esteem, to clinical depression or specific eating disorders like binge eating disorder and night eating syndrome. In some cases, underlying psychosis can be the drive of abnormal eating behaviour. Identification of these factors would lead to administration of appropriate treatment. Treatment of a co-morbid psychiatric disorders including administration of psychotropic medications and/or in other cases, tackling the weight related psychological issues could be a significant part of the management of obesity beside lifestyle modifications and antiobesity drug when indicated\(^8\).

In Malaysia, bariatric surgery has become available in more centres and may be the treatment of choice in some, particularly those diagnosed with morbid obesity and weight related comorbidities. In these cases, the importance of psychiatric evaluation pre- and post-surgery has been widely recognized. These aimed to 1) assess the presence and severity of psychopathology in patients for obesity surgery 2) evaluate the
change in psychopathology after surgery 3) identify factors that may be important for predicting outcome results 4) provide additional postoperative support/ facilitate if needed and 5) make appropriate recommendations regarding the patient’s suitability to undergo surgery.

A comprehensive psychiatric evaluation of patients presenting with obesity include 1) clinical interview 2) mental state examination 3) psychological tests (includes symptom inventories, e.g. for depression and eating disorders including binge eating assessment, objective personality and cognitive tests as deemed necessary by the psychiatrists). This is important to provide an objective measure of the presenting complaints, psychological adjustments and the patients’ preparedness for surgery and its long term commitment required post surgery. The outcome of a psychiatric assessment can be concluded in the form of several recommendations that include the need for pharmacotherapy, psychoeducation, psychotherapy to address any potential postsurgical barriers, close monitoring and the need for psychosocial support.

In conclusions, the need for multidisciplinary team which includes mental health professionals in treating obesity cannot be overemphasized. This has become an important rationale for an integrated approach and the call for “under one roof” treatment centre where all the team players have equally important roles and the same aims for their patients i.e. to achieve weight loss, maintain lower body weight, prevent weight gain and treat the underlying or related comorbidities.

References


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Personality Profiles of Malaysian Male Prisoners Convicted of Murder

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Abstract

Introduction: A review of the criminological literature indicates that some personality traits appear to develop and shape violent criminal behaviour. With this in mind, the present study was aimed to examine the personality profiles of Malaysian male murderers utilising the Alternative Five Factor Model (AFFM) constituting five personality traits: Activity, Sociability, Aggressiveness-Hostility, Impulsive Sensation Seeking, and Neuroticism-Anxiety. Methods: The present study was an observational cross-sectional study using a guided self-administered questionnaire. Items representing the five personality traits were assessed through the Malay version of Zuckerman-Kuhlman Personality Questionnaire-40-Cross Cultural Questionnaire (ZKPQ-M-40-CC). 71 male prisoners convicted of murder who are incarcerated in 11 Malaysian prisons were recruited. Descriptive item analyses were carried out to elicit the level of responses for each item in the ZKPQ-M-40-CC. Furthermore, the descriptive personality profiles using mean scores were performed. Results: The results indicated that the mean score of Activity (29.35, SD = 5.66) was higher than other personality traits. The mean score of Impulsive Sensation Seeking (21.65, SD = 6.48) and Aggressiveness-Hostility (21.65, SD = 6.48) were higher than the mean score of Neuroticism-Anxiety (17.96, SD = 5.51). Among the participants, 56.3% of them scored above the mean score (M = 26.54) for Sociability personality traits, which was the highest compared to other personality traits. 53.5% of the murderers scored equal or above the mean score (M = 6.48). Correlations among the five personality traits indicated several significant associations. Conclusion: In conclusion, the present study successfully identified the personality profiles of Malaysian male prisoners convicted of murder.

Keywords: Alternative Five Factor Model, Criminal Behaviour, Male Prisoner, Murder, Personality Profiles
Introduction

Investigating psychological aspects appear to be pivotal in understanding the ‘mind’ and psyche of criminals. There is a wide variety of theories and models that attempt to detect defects in the psychological aspects of the individual which may contribute to criminal behaviour. In Malaysia, psychological explanations for committing a crime especially violent crime like murder; have been largely neglected. As such, literatures focusing on psychological aspects of the criminals in Malaysia are too few to make reference to.

Nonetheless, several psychological aspects identified elsewhere; were accredited as underlying factors that are likely to trigger criminality within an individual. One of the important determinants in explaining criminality is the personality traits of that particular individual. For example, it is suggested that certain personality types such as neurotic extraverts and sensation seekers were inclined towards criminal and delinquent behaviour.

Classical study by Eynseck and Gudjonsson suggested there are several personality traits that highly inclined towards crime and criminal behaviour. Examples of personality traits that highly associated with criminal behaviour are neuroticism, extraversion, sensation seeking, aggression and interpersonal behaviour. Meanwhile, Zuckerman et al. proposed personality trait impulsive sensation seeking which characterised by impulsivity, risk taking, and low self-control as important trait of offensive behaviour. Although personality is not the only factor in shaping such offensive behaviour, there does seem to be a strong assertion that personality traits are relevant to a wide variety of behavioural domains, including criminality.

According to the Diagnostic and Statistical Manual of the American Psychiatric Association, personality traits are defined as the enduring patterns of perceiving, relating to, and thinking about the environment and oneself that are exhibited in a wide range of social and personal contexts. From the view of psychologists, personality is referred as a person’s unique long term pattern of thinking, emotions, and behaviour. It is worth noting that, personality profiles seem to be very useful in predicting the criminal behaviour and provide a better understanding of how an individual reacts to problems, make decisions and communicate with the surroundings.

As pointed out by Larsson, Andershed, and Lichtenstein, genetic and personality factors may be as highly powerful as environmental factors in explaining antisocial and violent behaviour in an individual. Such genetic and environmental risk factors may interact in significant ways. In addition, personality traits reflect stable behaviours that a person exhibits in most situations. Additionally, personality traits able to explain and most importantly can predict antisocial, criminal and delinquent behaviour. Therefore, it can be suggested that personality traits are major underlying determinants for criminality and antisocial behaviour.

Increased concerns about the rate of murder in Malaysia have called for studies examining personality profiles of the Malaysian murderers. However, studying personality traits and other psychological factors among Malaysian murderers has been generally ignored by researchers, partly due to the higher prevalence rates of less serious crimes in Malaysia and difficulty in gaining access to the research population. Therefore, the present study seeks to narrow the gap of knowledge regarding the
personality profiles of male prisoners who convicted of murder.

In general, murder is a form of criminal act that can be defined as illegal and intentional killing of a human being \(^{13}\). According to Blom-Cooper and Morris \(^{14}\), ‘malice aforethought’ is the key element in the legal definition of murder. Given the large number of evidence cited in this article, it appears that it is important to assess and identify the personality traits that contribute towards criminal behaviour among murderers. This is the first national study that was conducted among male prisoners who convicted of murder in order to obtain their self-reported personality profiles.

An empirical assessment of personality profiles among Malaysian murderers would contribute to the body of knowledge of the relevant disciplines, for example criminology, psychology, psychiatry, law, sociology and penology; and it is hoped that many key personnel will benefit from the outcomes of this study. In addition, the personality profiles that are generated from the present study may help to prevent and ameliorate similar criminal personality traits from at-risk and vulnerable groups of individuals.

**Methods**

**Study design and participants**

The present study adapted an observational cross-sectional methodology using a guided self-administered questionnaire for data collection. The sampling frame consisted of 71 Malaysian male murderers aged 21 and older. The participants were selected using purposive sampling method with predetermined selection criteria. The purposive method was largely due to the level of dangerousness posed by the inmates themselves and prison safety concerns.

The present study was carried out in eleven Malaysian prisons. Ethical approval and permissions were granted by the Malaysian Department of Prisons and the Human Ethical Committee of Universiti Sains Malaysia. The participation was on volunteer basis and the anonymity and confidentiality of their responses were assured and maintained. Written and signed consent from the participants were obtained prior to their participation.

**Measures**

The present study was conducted using a guided self-administered questionnaire. The questionnaire consisted of two sections: socio-demography of respondents and psychometric instrument based on Zukerman et al.’s \(^{4}\) Alternative Factor Model (AFFM). The contents of the questionnaire are as follows:

**Socio-demographic section**

This section was designed to identify the socio-demographic profiles of the participants. This section included items on participant’s age, ethnicity, religion, marital status, occupational and educational status. The marital and occupational status were based on the prior to incarceration. The socio-demographic variables were used for comparative purposes.

**Psychometric instrument**

In order to investigate the personality of criminals, psychologists and criminologists use a large number of models and concepts. A potential model that may explain underlying complexities of criminal behaviour is the AFFM introduced by Zuckerman et al. \(^{4}\). According to its authors \(^{4}\), the AFFM may be considered as culturally
universal as it asserts five basic factors that
describes and explains the personality traits
of individuals. AFFM offers a broad and
comprehensive framework for describing
normative personality traits of individuals
and provides a mechanism to compare traits
between criminal and non-criminal
populations.

AFFM was chosen over other personality
theories and models due to several reasons.
AFFM is viewed as a ‘revised’ version of
the original Five Factor Model (FFM), “Big
Five” and “PEN” (Psychoticism,
Extraversion, Neuroticism) based on a
comparative analyses conducted by
Zuckerman et al.4. It was found that FFM
and PEN were not sufficient enough to
accurately represent the personality trait of
individuals. The above rationales indicate
that there is a need to address the usage of
AFFM in the present study.

In order to reveal the personality profiles of
the Malaysian murderers using AFFM, the
Malay version of Zuckerman-Kuhlman
Personality Questionnaire-40-Cross Culture
(ZKPQ-M-40-CC) was used in this study.
This questionnaire was the simplified
version of ZKPQ-50-CC which consisted of
50 items15. The psychometric properties of
ZKPQ-M-40-CC were found to be valid and
reliable in the Malay language16. The overall
internal consistency of ZKPQ-M-40-CC was
0.7516.

ZKPQ-M-40-CC reflects AFFM which
assessed five types of personality traits such
as Activity (Act), Sociability (Sy),
Aggressiveness-Hostility (Agg-Host),
Impulsive Sensation Seeking (ImpSS), and
Neuroticism-Anxiety (N-Anx). All the items
of the questionnaire were answered using a
five-point Likert scale ranging from 1 (not at
all like me) to 5 (completely like me). Each
subscale had eight items respectively.

Analyses protocol

The analyses of the present study proceeded
along two directions. The first line of
analysis was descriptive analysis focusing
on item level analyses for each personality
trait items. This was followed by the mean
score of each trait within the AFFM. The
second line of analysis examined the
correlations between the personality traits
subscales. In respect of this, the associations
between the personality traits were
established using the Pearson correlation
coefficient test due the normal distribution
of the scores. The responses from collected
questionnaires were coded and the analyses
were performed using the Statistical
Package for Social Sciences (SPSS) version
20.0.

Results

Socio-demographic profiles of murderers

The total respondents from study group were
71 murderers incarcerated in eleven prisons
within Peninsular Malaysia. All of the
respondents were very cooperative and
participated until the end of the survey
exercise. The variables were as follows: age,
etnicity, religion, marital status,
occupational status, and educational status.

The age of respondents during commission
of murder ranged from 21 to 64 years old
with a mean age of 29.94 years old (SD =
10.76). Their ethnic backgrounds consisted
of 40.8% Malay, 33.8% Indian, 23.9%
Chinese, and 1.4% others. With regards to
religion, the majority (45.1%) of the
respondents were Muslims, followed by
Hindu (26.8%), Buddhist (22.5%) and only
5.6% were Christians. A high proportion of
respondents (46.5%) were single during the
commission of murder, 33.8% were married,
15.5% were divorced or separated from their partners and the rest were widower (4.2%).

Prior to their conviction, most of the respondents were working in semiskilled professions (59.2%) such as security guards, lorry drivers, labourers, and odd job workers. Meanwhile, 12.7% had worked in clerical or skilled professions. 11.3% respondents were considered not working. The same proportion was observed for respondents who were self-employed and engaged in business (11.3%). Four participants were former government employees.

As to highest level of education, 36.6% of the respondents achieved lower secondary education and 31.0% of them achieved upper secondary education. 25.4% completed primary education and only a small percentage of respondents had pre-university education (2.85) or diplomas (2.8%). Only one respondent was not formally educated.

Descriptive item level analyses

The descriptive item level analyses of each personality trait consisted of frequency distribution, mean and standard deviation (SD) for each item. The main purpose of this descriptive item level analysis for each item within each personality trait was to elicit the degree of responses among the murderers. The descriptive item level analyses are summarised in Table 1 until Table 5.

For the Activity trait, the mean scores ranged from 3.20 to 4.20 on a five-point Likert scale [Table 1]. The highest mean score was observed for items 8 and 4. Based on the content of these items, Malaysian murderers can be characterised as high energy people who led an active lifestyle prior to their arrest. They also tended to perform jobs until completion. In contrast, the lowest mean score was observed for item 2 in which the murderers perceived their lifestyle as not as busy compared to other people and as such have adequate free time for themselves.

Table 1. Frequency distribution, mean, and standard deviation of personality trait Activity of respondents (n = 71)

<table>
<thead>
<tr>
<th>Activity items in the ZKPQ-40-M-CC</th>
<th>SD (%)</th>
<th>D (%)</th>
<th>N (%)</th>
<th>A (%)</th>
<th>SA (%)</th>
<th>Mean*</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Saya tidak suka membuang masa saya hanya duduk bersenang-lenang</td>
<td>5.6</td>
<td>19.7</td>
<td>7.0</td>
<td>23.9</td>
<td>43.7</td>
<td>3.80</td>
<td>1.34</td>
</tr>
<tr>
<td>2. Kehidupan saya lebih sibuk daripada orang lain</td>
<td>12.7</td>
<td>23.9</td>
<td>14.1</td>
<td>29.6</td>
<td>19.7</td>
<td>3.20</td>
<td>1.35</td>
</tr>
<tr>
<td>3. Saya suka melakukan kerja sepanjang masa</td>
<td>4.2</td>
<td>21.1</td>
<td>18.3</td>
<td>33.8</td>
<td>22.5</td>
<td>3.49</td>
<td>1.18</td>
</tr>
<tr>
<td>4. Saya suka menjadi seorang yang aktif</td>
<td>1.4</td>
<td>7.0</td>
<td>12.7</td>
<td>38.0</td>
<td>40.8</td>
<td>4.10</td>
<td>0.97</td>
</tr>
<tr>
<td>5. Apabila bercuti atau bersiar-siar, saya suka melakukan aktiviti sukan</td>
<td>7.0</td>
<td>14.1</td>
<td>22.5</td>
<td>31.0</td>
<td>25.4</td>
<td>3.54</td>
<td>1.22</td>
</tr>
<tr>
<td>6. Saya suka melakukan aktiviti fizikal seperti buat kerja dan bersenam</td>
<td>5.6</td>
<td>12.7</td>
<td>21.1</td>
<td>32.4</td>
<td>28.2</td>
<td>3.65</td>
<td>1.18</td>
</tr>
<tr>
<td>7. Saya bertindak cergas dan aktif sebaik sahaja bangun dari tidur</td>
<td>4.2</td>
<td>21.1</td>
<td>29.6</td>
<td>22.5</td>
<td>22.5</td>
<td>3.38</td>
<td>1.18</td>
</tr>
<tr>
<td>8. Saya melakukan sesuatu kerja dengan bersungguh-sungguh</td>
<td>2.8</td>
<td>2.8</td>
<td>18.3</td>
<td>23.9</td>
<td>52.1</td>
<td>4.20</td>
<td>1.02</td>
</tr>
</tbody>
</table>

SD = Strongly Disagree, D = Disagree, N = Neither agree nor disagree, A = Agree, SA = Strongly Agree; *On a 1-5 scale, a high score reflect the intensity of active lifestyle.
With regards to the Sociability trait (see Table 2), the mean scores ranged from 3.01 to 3.65. The highest mean score was seen for items 6 and 3. Based on item 6 and 3, it can be viewed that murderers were active in social participation such as making friends and going out for social events. The least mean score was documented for two items: item 5 and 8 with mean score of 3.01 (SD = 1.21 and 1.34 respectively).

**Table 2.** Frequency distribution, mean, and standard deviation of personality trait Sociability of respondents (n = 71)

<table>
<thead>
<tr>
<th>Sociability items in the ZKPQ-40-M-CC</th>
<th>SD (%)</th>
<th>D (%)</th>
<th>N (%)</th>
<th>A (%)</th>
<th>SA (%)</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Saya meluangkan banyak masa bersama kawan-kawan</td>
<td>9.9</td>
<td>23.9</td>
<td>16.9</td>
<td>29.6</td>
<td>19.7</td>
<td>3.25</td>
<td>1.30</td>
</tr>
<tr>
<td>2. Saya tidak memerlukan ramai kawan</td>
<td>25.4</td>
<td>25.4</td>
<td>19.7</td>
<td>19.7</td>
<td>9.9</td>
<td>3.37</td>
<td>1.32</td>
</tr>
<tr>
<td>3. Saya tidak berasa selesa dalam majlis yang besar</td>
<td>18.3</td>
<td>40.8</td>
<td>23.9</td>
<td>9.9</td>
<td>7.7</td>
<td>3.54</td>
<td>1.12</td>
</tr>
<tr>
<td>4. Dalam sesuatu majlis, saya seronok bergaul dengan ramai orang</td>
<td>5.6</td>
<td>22.5</td>
<td>18.3</td>
<td>36.6</td>
<td>16.9</td>
<td>3.37</td>
<td>1.18</td>
</tr>
<tr>
<td>5. Saya suka bersendirian dan tidak suka diganggu</td>
<td>11.3</td>
<td>28.2</td>
<td>22.5</td>
<td>26.8</td>
<td>11.3</td>
<td>3.01</td>
<td>1.21</td>
</tr>
<tr>
<td>6. Saya seorang yang sangat peramah dan suka berkawan</td>
<td>2.8</td>
<td>11.3</td>
<td>28.2</td>
<td>33.8</td>
<td>23.9</td>
<td>3.65</td>
<td>1.06</td>
</tr>
<tr>
<td>7. Saya menghabiskan banyak masa bersendirian</td>
<td>23.9</td>
<td>28.2</td>
<td>18.3</td>
<td>16.9</td>
<td>12.7</td>
<td>3.34</td>
<td>1.35</td>
</tr>
<tr>
<td>8. Saya lebih suka melakukan sesuatu perkara seorang diri</td>
<td>14.1</td>
<td>26.8</td>
<td>25.4</td>
<td>14.1</td>
<td>19.7</td>
<td>3.01</td>
<td>1.34</td>
</tr>
</tbody>
</table>

SD = Strongly Disagree, D = Disagree, N = Neither agree nor disagree, A = Agree, SA = Strongly Agree; *On a 1-5 scale, a high scores reflects the level of sociability of the respondents.

In Table 3, the item analysis for the Aggressiveness-Hostility trait is shown. The mean score ranged between 1.85 and 2.99. Compared with Activity and Sociability traits, the mean score for Agg-Host seemed to be lower. Among the items in Agg-Host, item 5 recorded the highest mean score of 2.99 (SD = 1.40). This finding reflected the anger component of murderers’ dominant personality trait in which they are easily triggered into angry verbal outbursts or behaviours.

It is also worth noting that, items 6, 7, and 8 recorded higher mean scores (2.97 respectively) compared to item 1 (2.83), item 2 (2.31), item 3 (1.92), and item 4 (1.85). Based on items 7 and 8, it appears that murderers are relatively short tempered. Item 8 also reflected the degree of verbal aggressiveness among Malaysian murderers. Surprisingly it emerged that the respondents perceived themselves to be patient with other people even though their feelings had been hurt by these people (see item 6). This bears more research in future.
Table 3. Frequency distribution, mean, and standard deviation of personality trait Aggressiveness-Hostility of respondents (n = 71)

<table>
<thead>
<tr>
<th>Aggressiveness-Hostility items in the ZKPQ-40-M-CC</th>
<th>SD (%)</th>
<th>D (%)</th>
<th>N (%)</th>
<th>A (%)</th>
<th>SA (%)</th>
<th>Meana</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Apabila saya marah, saya mengeluarkan kata-kata yang tidak baik</td>
<td>26.8</td>
<td>15.5</td>
<td>19.7</td>
<td>23.9</td>
<td>14.1</td>
<td>2.83</td>
<td>1.42</td>
</tr>
<tr>
<td>2. Apabila saya marah, biasanya saya akan mencarut atau menyumpah</td>
<td>40.8</td>
<td>21.1</td>
<td>14.1</td>
<td>14.1</td>
<td>9.9</td>
<td>2.31</td>
<td>1.39</td>
</tr>
<tr>
<td>3. Saya seringkali rasa seperti hendak memukul seseorang</td>
<td>52.1</td>
<td>25.4</td>
<td>5.6</td>
<td>12.7</td>
<td>4.2</td>
<td>1.92</td>
<td>1.22</td>
</tr>
<tr>
<td>4. Saya bersikap kasar terhadap orang yang tidak suka</td>
<td>50.7</td>
<td>22.5</td>
<td>18.3</td>
<td>0.0</td>
<td>8.5</td>
<td>1.85</td>
<td>1.01</td>
</tr>
<tr>
<td>5. Jika seseorang membuat saya marah, saya akan memarahinya semula</td>
<td>18.3</td>
<td>23.9</td>
<td>16.9</td>
<td>22.5</td>
<td>18.3</td>
<td>2.99</td>
<td>1.40</td>
</tr>
<tr>
<td>6. Saya sentiasa bersabar dengan orang lain meskipun mereka menyakiti saya</td>
<td>11.3</td>
<td>26.8</td>
<td>26.8</td>
<td>18.3</td>
<td>16.9</td>
<td>2.97</td>
<td>1.26</td>
</tr>
<tr>
<td>7. Saya seorang yang panas baran</td>
<td>19.7</td>
<td>16.9</td>
<td>28.2</td>
<td>16.9</td>
<td>18.3</td>
<td>2.97</td>
<td>1.37</td>
</tr>
<tr>
<td>8. Apabila orang menengking saya, saya akan menengking mereka semula</td>
<td>18.3</td>
<td>22.5</td>
<td>19.7</td>
<td>22.5</td>
<td>16.9</td>
<td>2.97</td>
<td>1.37</td>
</tr>
</tbody>
</table>

SD = Strongly Disagree, D = Disagree, N = Neither agree nor disagree, A = Agree, SA = Strongly Agree; *On a 1-5 scale, a high scores reflects the readiness to be aggressive.

The fourth item level analysis was performed for Impulsive Sensation Seeking (ImpSS) trait as shown in Table 4. Based on the analysis, it was found that item 2 recorded the highest mean score of 3.20 (SD = 1.21) followed by item 5 (Mean = 3.07, SD = 1.48). Meanwhile the least mean score was noted for item 1 with the mean score of 1.85 (1.01).

Table 4. Frequency distribution, mean, and standard deviation of personality trait Impulsive Sensation Seeking of respondents (n = 71)

<table>
<thead>
<tr>
<th>Impulsive Sensation Seeking items in the ZKPQ-40-M-CC</th>
<th>SD (%)</th>
<th>D (%)</th>
<th>N (%)</th>
<th>A (%)</th>
<th>SA (%)</th>
<th>Meana</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Apabila orang tidak bersetuju dengan saya, saya akan bergaduh dengan mereka</td>
<td>52.1</td>
<td>18.3</td>
<td>22.5</td>
<td>7.0</td>
<td>0.0</td>
<td>1.85</td>
<td>1.01</td>
</tr>
<tr>
<td>2. Saya sering melakukan sesuatu perkara mengikut kehendak hati</td>
<td>11.3</td>
<td>15.5</td>
<td>31.0</td>
<td>26.8</td>
<td>15.5</td>
<td>3.20</td>
<td>1.21</td>
</tr>
<tr>
<td>3. Saya ingin pergi melancong tanpa sebarang perancangan</td>
<td>21.1</td>
<td>14.1</td>
<td>22.5</td>
<td>32.4</td>
<td>9.9</td>
<td>2.96</td>
<td>1.31</td>
</tr>
<tr>
<td>4. Kadang-kadang saya suka melakukan perkara-perkara yang sedikit menakutkan</td>
<td>23.9</td>
<td>21.1</td>
<td>15.5</td>
<td>23.9</td>
<td>15.5</td>
<td>2.86</td>
<td>1.43</td>
</tr>
<tr>
<td>5. Saya akan mencuba apa-apa sahaja, sekurang-kurangnya sekali</td>
<td>21.1</td>
<td>16.9</td>
<td>19.7</td>
<td>18.3</td>
<td>23.9</td>
<td>3.07</td>
<td>1.48</td>
</tr>
<tr>
<td>6. Saya kadang-kadang melakukan perkara-perkara yang ‘gila’ hanya untuk berasa seronok</td>
<td>32.4</td>
<td>22.5</td>
<td>15.5</td>
<td>18.3</td>
<td>11.3</td>
<td>2.54</td>
<td>1.40</td>
</tr>
</tbody>
</table>
Based on the contents of items 2 and 5, Malaysian murderers seemed to act on impulse. Here, impulsivity can be defined as a personality trait that refers to behaving without giving it much thought, without considering potential future consequences, as if one is motivated only by concerns of pleasure or reward\textsuperscript{17}. In addition, they can also be considered as risk takers as they want to try out things at least once in their lifetime. From the dispersion of responses in item 7, Malaysian male murders are likely to be involved in new activities perceived as fun without weighing their consequences.

As for Neuroticism-Anxiety (N-Anx), the mean scores ranged from 1.65 to 3.14 and the highest mean score was found for item 2 (Mean = 3.14, SD = 1.37). Based on item 2 responses, it was found that the murderers are sensitive and are easily emotionally hurt by other people's action or words. This is quite worrisome as it is higher compared to other N-Anx characteristics. Together with the results found in the Aggressive-Hostility (Agg-Host) trait, the implication points to depicting a psychological profile that is reminiscent of anti-social, fault finding, and prone to violence at the least provocation. These results are summarised in Table 5.

**Table 5.** Frequency distribution, mean, and standard deviation of personality trait Neuroticism-Anxiety of respondents (n = 71)

<table>
<thead>
<tr>
<th>Neuroticism-Anxiety items in the ZKPQ-40-M-CC</th>
<th>SD (%)</th>
<th>D (%)</th>
<th>N (%)</th>
<th>A (%)</th>
<th>SA (%)</th>
<th>Mean*</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Badan saya sering berasa tidak selesa tanpa sebarang sebab yang munasabah</td>
<td>42.3</td>
<td>25.4</td>
<td>22.5</td>
<td>8.5</td>
<td>1.4</td>
<td>2.01</td>
<td>1.06</td>
</tr>
<tr>
<td>2. Saya mudah sensitif dan mudah terluka dengan kata-kata dan tindakan orang lain</td>
<td>12.7</td>
<td>26.8</td>
<td>15.5</td>
<td>23.9</td>
<td>21.1</td>
<td>3.14</td>
<td>1.37</td>
</tr>
<tr>
<td>3. Saya mudah berasa takut</td>
<td>26.8</td>
<td>45.1</td>
<td>8.5</td>
<td>16.9</td>
<td>2.8</td>
<td>2.24</td>
<td>1.11</td>
</tr>
<tr>
<td>4. Kadang-kadang saya berasa cemas</td>
<td>26.8</td>
<td>35.2</td>
<td>18.3</td>
<td>12.7</td>
<td>7.0</td>
<td>2.38</td>
<td>1.21</td>
</tr>
<tr>
<td>5. Saya sering berasa tidak pasti dengan diri sendiri</td>
<td>32.4</td>
<td>26.8</td>
<td>18.3</td>
<td>16.9</td>
<td>5.6</td>
<td>2.37</td>
<td>1.26</td>
</tr>
<tr>
<td>6. Saya sering berasa hendak menangis tanpa sebab</td>
<td>66.2</td>
<td>14.1</td>
<td>11.3</td>
<td>5.6</td>
<td>2.8</td>
<td>1.65</td>
<td>1.07</td>
</tr>
<tr>
<td>7. Saya sering berasa tidak selesa dan tidak sihat tanpa sebab yang munasabah</td>
<td>47.9</td>
<td>32.4</td>
<td>14.1</td>
<td>4.2</td>
<td>1.4</td>
<td>1.79</td>
<td>0.94</td>
</tr>
<tr>
<td>8. Saya sering berasa kecewa</td>
<td>29.4</td>
<td>21.1</td>
<td>12.7</td>
<td>15.5</td>
<td>11.3</td>
<td>2.38</td>
<td>1.43</td>
</tr>
</tbody>
</table>

SD = Strongly Disagree, D = Disagree, N = Neither agree nor disagree, A = Agree, SA = Strongly Agree; *On a 1-5 scale, a high score reflects the neurotic-anxiety nature of the respondents.

**Descriptive mean scores**

The distribution of scores of ZKPQ-M-40-CC showed that the mean score of Activity (29.35) was higher than other personality traits. This was followed by the mean score of ImpSS (21.65) was higher than Agg-Host (20.80) and N-Anx (17.96); an important
distinction in formulating Malaysian murderer profiles. 53.5% of the murderers scored equal or above the mean score (M = 6.48) in the ImpSS personality traits suggesting the higher prevalent of such a personality trait among the sample of murderers. This is in accordance with previous literature in which impulsivity is widely correlated with non-psychopathic murder\(^{18}\). Among the participants, 56.3% of them scored above the mean score (M = 26.54) for Sociability personality traits, which was considerably high. The results were tabulated in Table 6.

Table 6. Descriptive scores of personality traits of the respondents (n = 71)

<table>
<thead>
<tr>
<th>Psychological profiles</th>
<th>Mean (SD)</th>
<th>Frequency ≥ mean score n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Activity</td>
<td>29.35 (5.66)</td>
<td>39 (54.9)</td>
</tr>
<tr>
<td>Sociability</td>
<td>26.54 (5.09)</td>
<td>40 (56.3)</td>
</tr>
<tr>
<td>Aggressiveness-Hostility</td>
<td>20.80 (7.31)</td>
<td>33 (46.5)</td>
</tr>
<tr>
<td>Impulsive Sensation Seeking</td>
<td>21.65 (6.48)</td>
<td>38 (53.5)</td>
</tr>
<tr>
<td>Neuroticism-Anxiety</td>
<td>17.96 (5.51)</td>
<td>33 (46.5)</td>
</tr>
</tbody>
</table>

Descriptive statistics were used to determine the descriptive scores and prevalence of each psychological trait among Malaysian male murderers. Here, the scores equaled to or higher than the mean score were considered high for the particular psychological measure\(^{19}\). Based on the number of respondents who obtained equal or more than the mean scores for personality traits, Sociability and Activity traits are the most prevalent among the sample of murderers. According to AFFM, the personality trait Sociability can be viewed as individuals who prefer social activities and are outgoing. In addition, these individuals also love to communicate and interact with the surrounding people whether they know them or not, and tend to have many circles of friends and exhibit intolerance for social isolation\(^4\).

The high prevalence of Activity trait indicates that Malaysian murderers are individuals who prefer work activity, yet are impatience, and restless\(^4\). The preference for challenging hard work and a requirement for a lot of working energy are also characteristics which fall under this personality trait. Individuals who exhibit a strong trait of Activity are quite similar to Type A individuals who characterised as active individuals and tend to face difficulties in relaxing.

Activity trait is also associated with several negative outcomes. Individuals who are active tend to lack self-control. According to Gottfredson and Hirschi\(^{20}\) individuals with low self-control tend to be impulsive, insensitive, short-sighted, risk takers and most importantly are physically active. Having high scores in the Activity trait may explain why the research respondents get involved in violent behaviours and murder.

In addition, the findings suggest that ImpSS is the third most prevalent personality trait. The ImpSS trait reflects individuals who lack planning and crave the gratification for impulsive actions. Individuals with high scores on ImpSS tend to act fast on impulse and have high desire for thrills, excitement and seek novelty\(^4\). This trait explains the preference for unpredictable situations and friends\(^4\).

According to AFFM, individuals with ImpSS manifest strong traits of low self-
control. As such, the higher score of ImpSS among murderers may increase the tendency to act on impulse and consequently influence criminal involvement. This is in agreement with previous studies in which strong associations were found between impulsivity and a wide range of troubles such as childhood conduct problems and prediction of adult criminality and also non-psychopathic murder.

**Correlations among personality traits**

In order to establish the association between personality traits among Malaysian murderers, Pearson correlation coefficient was employed. The result of association is summarized in Table 7. The findings evidenced several significant associations among the personality traits in the sample of Malaysian murderers.

The highest value of correlation was observed for ImpSS with Agg-Host \( r = 0.61, p<0.001 \). The significant correlation between ImpSS and Agg-Host is supported by previous study as impulsivity highly associated with wide range of aggressive behaviour [23]. The next highest correlation was noted for personality trait ImpSS with N-Anx \( r = 0.33, p<0.001 \). This particular finding is congruent with previous literature in which neuroticism highly reflects impulsivity, instability, and other antisocial behaviour.

Significant correlation was also noted between N-Anx and Agg-Host pair with \( r = 0.28 \) at the significance level of 0.05. Earlier research found similar results. High scores in neuroticism positively predicted aggressive behaviour especially verbal aggression. Interestingly, a negative correlation was observed between personality trait Activity and Agg-Host \( r = -0.28, p<0.05 \). Individuals with higher Activity trait appeared to exhibit lesser aggressive traits, at least in the Malaysian context.

**Table 7. Pearson correlation coefficients between personality traits**

<table>
<thead>
<tr>
<th>Measures</th>
<th>(1)</th>
<th>(2)</th>
<th>(3)</th>
<th>(4)</th>
<th>(5)</th>
</tr>
</thead>
<tbody>
<tr>
<td>(1) Activity</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(2) Sociability</td>
<td>0.00</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(3) Aggressiveness-Hostility</td>
<td>-0.28*</td>
<td>0.00</td>
<td>1.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(4) Impulsive Sensation Seeking</td>
<td>-0.20</td>
<td>0.12</td>
<td>0.61**</td>
<td>1.00</td>
<td></td>
</tr>
<tr>
<td>(5) Neuroticism-Anxiety</td>
<td>-0.02</td>
<td>-0.07</td>
<td>0.28*</td>
<td>0.33**</td>
<td>1.00</td>
</tr>
</tbody>
</table>

Note: *p<0.05, **p<0.001

The present study had several limitations. Since the present study recruited the respondents using purposive sampling method, the results cannot be generalised to the overall population of Malaysian male prisoners who convicted of murder. Another limitation of the present study is the nature of this study. The present study relies heavily on self-reported information from the respondents themselves. Therefore, the result of the present research must be interpreted with acknowledged limitations. Despite of these limitations, the present study had successfully contributed valuable input on personality profiles of male prisoners convicted of murder.

**Conclusion**

The present study was a purposive sample of 71 Malaysian male prisoners who convicted of murder (murderers). While the present
study only recruited 71 murderers as the subjects of the study, it was not the intention of this study to generalise the whole murderers’ population in Malaysia. Rather, it was a ground-breaking study which intended to explore the personality profiles of Malaysian male prisoners who convicted of murder. The results indicated that Sociability, Activity, and Impulsive Sensation Seeking traits are prevalent personality traits. Significant correlations were noted among these pairs: Activity - Agg-Host, Agg-Host - ImpSS, Agg-Host - N-Anx, and ImpSS-N-Anx.

As a conclusion, the present study achieved its aims by establishing the personality profiles of Malaysian murderers via descriptive and inferential analyses. Identifying the personality traits among sample of murderers are vital as it helps to formulate a better understanding of the characteristics of murderers and determine areas for constructive awareness at the individual, family, and societal levels. This will also act as part of proactive measures that can be taken to ameliorate criminal personality traits among at-risk individuals via various prevention, intervention and rehabilitation efforts.

Acknowledgement

The authors would like to express their sincerest gratitude and thanks to Universiti Sains Malaysia and the USM Vice Chancellor Award Programme for supporting this study. Appreciation is also extended to the Malaysia Department of Prisons for allowing the researchers to conduct this study. The authors also thank Kpj Dato’ Alzafry Mohamed Alnassif and TKPj Supri Hashim for their valuable support and encouragement. The authors thank all the participants for their participation and unlimited cooperation in making this study successful.

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Care Demands-related Concerns and Perceived Service Needs of Families of People with Mental Illness in the Community

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Abstract

Owing to reduced inpatient stays, people with mental illness (PMI) were often discharged from the hospital in ‘acute’ conditions. During this transition period of fragility, the relocation of care from hospital to home has tremendous impact on every aspect of a family’s life as they need to face a challenging task of caring especially when they are ‘not ready’ and ‘ignorant’ about the chronicity and severity of the illness. Furthermore, where economic and psychological support is concerned, those who are undertaking this task may require significant professional guidance. Aims: This study examines the experiences of 100 families in caring for people with mental illness in the community. Methods: Qualitative interviews were conducted in their homes within three Malaysian states of Sabah, Sarawak and Johor in year 2013. Results: Three themes emerged from the findings of ‘care demands related concerns’ of these families. These include theme (1): care provision related concerns of families which were related to the needs of people with mental illness for continuing care provision, their non-compliance with medication and relapse, altered sleep pattern, limited self-care ability, behavioral problems and also social isolation. Theme (2): perceived availability of resources of service provision/support which were related to activities planned for the families before the discharge of the people with mental illness and theme (3): family members perceived service needs whereby they informed of their needs such as continual health care through home visit, provision of financial aid, job coach service, centre for care provision of PMI and rehabilitative programs.

Keywords: Community, People with Mental illness, Non-compliance, Relapse, Social Isolation

Introduction

Mental illness in one family member can impact on various aspect of the family life: work, income, leisure time, personal health and social relationship with friends, neighbors, colleagues and even extended family. Experiences of social isolation resulting from their avoidance of family celebrations or other recreational activities are common. Furthermore, marital discord and family conflicts may increase
dramatically. Siblings and their parents’ experience of fears, difficulties in functioning and significant grief reactions which required counseling or medical attention have been reported.  

The family who are managing a person with mental illness at home may be threatened by the need for a regular routine for instance, they may need to contend with reverse sleep cycles as the person may sleep all day and be awake during the night. One of the more insidious stressors experienced by the family was the lack of opportunity to ‘let off some steam’ to vent their tremendous frustrations and disappointments associated with mental illness. Therefore, the family who manage people with mental illness at home may be seen by others as sacrificing their lives, martyring themselves.

Hence, in this era of shortened hospital stays, plans of how best to effect a smooth transition of continuity of care from hospital into the community is of imperative significance. This is because, a stressful transition coupled with unmet needs could lead to vulnerability, decompensation, poor reintegration into the community and ultimately re-admission to hospital. Moreover, the families still needed the support not only in the continuity of care but especially so in times of crisis or when they feel depleted emotionally or physically hence unable to carry on.

**Background**

With the objective to reduce stigmatization of the illness and deinstitutionalization of the people with mental illness (PMI), the locus of care has moved from hospital care to be in the community since about two decades ago. With shorter inpatient stays, PMI often leave the hospital in acute conditions with the needs for prompt and focused care from their families which include the needs to manage the frequent crises due to the chronic nature and severity of the illness, lower level of social adaptive and other functions.

In Malaysian setting, when a person with mental illness is discharged from the ward, he/she is directly brought back to their home and into the community. The family members who are either equipped with or without the knowledge on how to ‘care’ for them at home need to ‘accept’ the responsibilities of caring. It is very common to hear that the family members are actually ‘scared’ of the patient but they have no choice. Hence, family members who live with people with mental illness may be ‘at the edge of psychosis all the time’ or living with constant fear which is not healthy. In addition, they will be varied in their capacity for socialization due to stigma. While some were isolated to the point of being reclusive, suffered from depression, alcohol abuse and chronic medical conditions, while others, socialized inappropriately or engaged in high risk behavior including substance abuse as a result of stress.

This relocation of care from hospital to home of the PMI has tremendous impact on every aspect of the families as carers. These include their work life, income, leisure time, personal health and social relationship with others. Families’ experiences of social isolation resulting from their avoidance of family celebrations or other recreational activities are common. There is an increased marital discord and family conflicts; siblings and their parents experienced fears, difficulties in functioning and significant grief reactions. Families might need professional guidance and supports.

This is an interesting phenomenon to
explore whereby the magnitude of the problem whereby family who live with people with mental illness need to learn to become ‘expert’ in pharmacological as well as psychosocial rehabilitation. An appropriate and effective home-based and community support systems need to be coordinated to play a central role for smooth collaboration, cooperation and communication between the family, professional caregivers and people with mental illness. This will help to minimize the gap that appears among the elements of an uncoordinated psychiatric system and fragmented services resulting in the families to be in the dark, feeling isolated and not knowing what to do next.

This study hopes to strengthen/add on to the knowledge and insights on the care and facilitate an evidence-based decision making in relation to continual care provision for PMI after their discharge from the hospital into the community setting.

**Aim**

This study aimed to examine the experiences of caring for the PMI in the community.

**Methods**

A qualitative approach was adopted to explore the families’ experiences of caring for people with mental illness in the community. The families of PMI were interviewed using the interview question guide which explored the predefined topic in greater length and depth. The researcher gains the understanding of their views by using a language that was natural and understood by them.

Before conducting this study, ethical consideration had been sought from the Medical Research and Ethics Committee; Ministry of Health and the National Medical Research Register. A series of informal meetings and phone calls with the senior personnel of the mental institutions were done in order to gain organizational support and indirectly helped in the recruitment of participants. Only families who consented to participate in the study were recruited.

**Study settings and recruitment of participants**

100 families were recruited based on a non-probability, purposive sampling. To ensure that maximum variations of family’s perspectives of care experiences, families for this study who were of various ethnicities were recruited from three selected government hospitals in the States of Sarawak, Sabah and Johor. Register of names of PMI who were under the community follow-up care team home visits were screened through as a way to access their families. Sample size was determined by data saturation. Interviews were stopped when no new theme could be derived from the data.

**Data collection**

Data collection was conducted between July 2013 to November 2013 in the participants’ home after prior informed consent for participation was obtained. The interview was done face to face and audio-recorded in their homes. All interviews, each lasting from about half to one hour, were conducted in English, Bahasa Malaysia, Sarawak local dialect and Iban language. Field notes were also taken immediately after the interview.

**Data Analysis**

Textual data from the interview were thematically analyzed to obtain an in-depth understanding of the experiences of families caring for people with mental illness in the community. This involved preparing and organizing of textual data for analysis, reading through textual data, coding to
generate themes, representation of themes and interpretation.

Results

Theme (1): Care provision-related concerns of families

a. Lack of confidence for continual care provision

There is an issue of lack of confidence for continual care provision of the PMI who were discharged from the hospital. In particular, families perceived it as a challenge when they had to deal with the PMI’s behaviour. This caused them to be discouraged and fatigued with the caregiving role as evidenced from the following excerpt.

*The hospital should keep him a little longer. We don’t really know how to deal with him at home especially when he can just turn violent. I just don’t know how to describe to you when this happens.*

Sometimes, he did not want to take his medicine....when I ask him to take, he will get angry with me. Sometimes, he will just slam his room door.

b. Behavioural related concerns

One of the concerns of family members in their care provision of PMI who were discharged from hospital was behavioural-related. These include the PMI’s nature of being hot tempered or easily irritated or angry as illustrated by the following excerpts:

*If we ask her to help with house chores, she will do....but need to be asked to do...and sometimes she just got angry when being asked.*

He smokes a lot... he will get angry if there is no cigarette.

He can just turn violent. I just don’t know how to describe to you when this happens.

The family members noted that it was a burden to them when the PMI under their care smoked a lot and this added to their financial expenses as illustrated in the following excerpts:

*Oh...he smokes a lot...I need money to have the stock of cigarettes... otherwise he will get angry if there is no cigarette.*

He always want to smoke. As he has no money, I have to buy him the cigarettes. You know, now that the cost of the cigarettes has increased....so, it pinches on my budget most of the time. But yet, I have no other choice but to buy the cigarettes.

c. Concern related to non compliance with medication and relapse

Issue related to PMI’s non-compliance with medication and relapse is one of the most prominent issues encountered. The family members had to supervise and coax the PMI to take their medication as illustrated in the following quotes by the mothers:

*Sometimes she takes her medicine and sometimes she didn’t...or she misses a pill or two.*

*Sometimes she just did not want to take her medication.*

I need to crush the pills and mix with her food, otherwise, the medicine will be just left lying there. If she know about me mixing her food with the medicine, she don’t want to take the food also.
d. Concerns of altered sleep-wake pattern

Most of the time, the PMI slept during the day.

Since she is discharged from hospital, she is doing nothing....sleeping most of times.

He sleeps a lot especially during the day....but at night, he will sleep very late. Sometimes he sleeps at 5 am in the morning when I wake up to prepare breakfast for the family.

He likes to wander around especially at night and came home late which worried the family members.

e. Concern of limited self care ability

Family members expressed their concerns about the PMI’s self care ability due to the altered level of cognitive functions and limited awareness of dangers as indicated by the following quote:

He likes to wander around especially at night and came home late which worried the family members.

He smokes a lot. Most of the time, he just throw the cigarettes butt anywhere. One time I caught him throwing part of his unfinished cigarette on his bed. What worries me is that, this poses danger not only to him but all of us.

Some mothers indicated their concerns as they still need supervision in relation to their own hygiene needs, as stated by one mother:

He does’n’t like to take bath...have to force him.

f. Concerns related to tendency of social isolation

Another of the concerns as expressed by some of the family members was related to the tendency of social isolation among the PMI who did not talk much but and kept to themself most of the time:

Most of times, she keeps to herself in her room...don’t know what she is doing there. He does not have any friends since his illness sets on him.

He refused to meet with his friends. Looks like, he prefers to be on his own.

He is not interested to be involved in any activity especially those involving a lot of people....so he will stay at home and sleep.

g. Lack of family resources for continual care provision

Family members expressed their preference for PMI to be continued with hospital care due to problems of not having adequate family resource for continual care provision of family member who are PMI at home. The following quote is illustrative:

There is nobody to take care of him at home as all of us have our own responsibilities ....both of us are working while the other siblings are either working or at school....so if possible, better (for him) to be staying at the hospital as there are staffs who know how to take care of the patient there.

Its better for him to be at the hospital. There is nobody to look after him at home while everybody is at work. I am scared to leave him on his own without any supervision.
h. Positive and supportive of early discharge from hospital

However, there are also family members who viewed that if the PMI’s condition is stable, it is good for the PMI to be at their own home as family can take care of them.

If her condition is stable, then there is no reason for her to stay at the hospital. I want her to stay at home with me because she is my daughter. I can take care of her at home and I can see how she is getting on.

I can see that my son is doing fine as long as he takes his medicine. I would prefer my son to be at home with me because I am worried that he will be lonely at the hospital. At home, I can take care of him.

Theme (2): Perceived availability of resources of service provision / supports

Various kinds of activities were being planned for the families before PMI are being discharged from the hospital. The common activities include health education and family therapy whereby the families need to understand the nature of the illness, the importance of drug compliance, what they should do in case of emergency or if patient relapses.

When he is admitted, the doctor tells us about his illness. Before discharge, we are being informed about the importance of drug compliance and follow up care.

The staff were very kind. They asked me and the other families to attend family therapy which I find very useful in understanding my son’s illness.

Theme (3): Family members’ perceived service needs

With regards to the various problems/issues as encountered by families of PMI, these families perceived the needs for formal service provisions. These include the needs such as continual health care through home visit, provision of financial aid, job coach service, centre for care provision of PMI and rehabilitative programs.

a) Continual health care: home visit

Majority of the families recommended that they still need the health professionals’ care provisions. These include doing home visits to monitor the PMI’s condition, and providing assistance with counseling the PMI, in particularly their medication. As requested by one mother:

If possible, the hospital staff to continue doing home visits to their home so that I have somebody to ask if I have problems or doubts….like medication.

However, there are families who were reluctant for health professionals from clinic or hospital to visit their homes due to fear of being stigmatized by the neighborhood.

I don’t like the staff coming to our home. Otherwise, all my neighbors will know that our brother is mentally ill. I will bring him to the hospital for follow up.

b) Provision of financial aid

Formal support from the social welfare agency for families in term of financial aid is deemed a need as most of the PMI depended on their families. As lamented by one family member:
If possible, financial aid is given by the government for this type of people with mental illness...our family are poor...no money to cater for his needs...especially he likes to smoke...yet he is not working...depending on me to give him money to buy his cigarettes...so difficult like this.

c) Job coach support service

Formal support such as job coach service for job placement where possible for the PMI who are stable and independent are very much desired by the families. The following quote is illustrative:

If the government can provide or have job placement for people with mental illness is very good...my son is stable and independent....just that nobody want to take him to work.

d) Centre for care provision

Some families recommended a nursing home or centers which are affordable whereby those who are unable to take care or nobody to take care at home can send their relatives who are mentally ill to be cared for. As voiced out by one family member:

Nobody to take care of him here...you can see that my mother is old already and needed care too...and here another one like this...difficult...if the government can provide a center which is affordable would be good....as there are staff to take care of this kind of people.

e) Rehabilitation program

Invariably, a rehabilitation center is of importance to improve functions of the PMI in the community, as reiterated by one family member:

The hospital needs to have rehabilitation program, which cater to the needs of the patient.

Discussion

The discharge of people with mental illness from hospital into the community posed a challenging time for both people with mental illness as well as their families. For many PMI, residual symptoms may still remain and despite follow up care arranged for them, transition experiences from hospital to community often is experienced as being complex and disturbing.

Family members viewed that if the PMI’s condition is stable, it is good for them to be at their own home as family can take care of them. This finding is consistent with previous research whereby if patients felt supported by their family members, this can be a key feature in the successful adjustment to the community after discharge. However, some family members viewed that it is better for the patient to be in the hospital as there are hospital staff who knew how to take care of patients. Moreover, if the patient is in the hospital, they are confident that the patient is in “good hands” especially when they have nobody to take care of the patient at home.

Generally, family members expressed that they are not confident of taking care of the PMI at home related to behavioral control and administration of medications. They perceived they do not know how to control patient’s behavior especially when they turn aggressive or show their temper which caused them to be discouraged and fatigued with the caregiving role. This suggest that family interventions targeting symptoms management and their roles in medication
adherence seem warranted. This is consistent with findings by Nehra, Chakrabarti, Kulhara & Sharma, (2005)\textsuperscript{12} found that family coping styles can be identified and used to plan interventions to reduce the burden of family members who help to manage the patient at home. This is because successful management largely depends upon family support.

Psychological distress related to the caregiving role and burnout of families over time should not be neglected as this issue requires a more consistent intervention to ensure continuous support to communicate treatment goals related to overall patient functioning and integration into the community. This finding is consistent with findings by Saunders (2003)\textsuperscript{13} who suggested that mental health professionals should assist both patients and their caregivers in their recovery-oriented services such as strategies for relieving symptoms through educating about role of medications. This is due to the fact that variables associated with recovery include domains such as life satisfaction, hope and optimism, knowledge about mental illness and recovery and empowerment.\textsuperscript{5}

Where problems faced by family members were concerned, there was a consistent tone of frustration and discouragement as family described situations as worrisome. The needs related to management of symptoms, compliance to medication and other specific needs include those related for structured activities, employment, self-care and hygiene. Since patients and families accepted their discharge and follow up plans, a comprehensive plan of care which include family involvement would enlist treatment goals of the programs for the patient. Therefore, the focus of supportive family education such as more intensive behavioral family therapy for developing carer competence is deemed of significance not only to reduce carer stress and burden, but to improve coping, social support and quality of life.\textsuperscript{14-16}

**Recommendations**

Comprehensive treatment programs that address financial, occupational and social factors for patients with mental illness need to be focused on their needs. The elements of intervention should be carer focused, patient focused or both. This is to ensure that the targeted outreach program and the community follow up care consistently provide structure and ongoing professional support to both the people with mental illness and their families.

As the front line professionals who are in direct contact with people with mental illness and their family in the community setting, nurses may have to be trained to deliver more intensive interventions such as family support, family therapy and community support with the aim to improve coping hence reduce carer burden and improved mental health. The focus of supportive family education should move beyond information giving to developing coping strategies and support mechanisms for family members that enhanced the quality of life.\textsuperscript{17}

As for rehabilitation services, it should be focused on a culturally sensitive model with particular emphasis on education, work and independence as these would restore health and social functioning while establishing and maintain valued social roles. The users should not be passive players in the rehabilitation landscape but active participants shaping, as well as being shaped by, socio-medical pathways using personal coping mechanisms.
Conclusion

With the early discharge of people with mental illness into the community, an effective discharge planning is necessary to facilitate the transition period from hospital to community care. A personalized, comprehensive and structured discharge care plan is deemed important and requires attention not only to reduce relapse rates but assist people with mental illness to function at their best in the community. In addition, social support particularly as part of aftercare arrangements should aim to provide both practical assistance, information and general support such as skills training and interpersonal effectiveness. Adequate staffing, resource provision, organizational commitment and education of staff are an integral component of ‘discharge pack’ services to improve the continuity of service delivery and care between hospital and community mental health settings.

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Associated Factors of Sex Offenders

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Abstract

Objective: The aim of this study is to determine the risk factors for sex offenders. Methods: This is a cross sectional study comparing two groups using a combination of survey methodology and personal interviews. The data was collected over a period of six months from January 2004 until June 2004. All convicted sex offenders in respective prisons who are available until July 2004 was included in the study. A control group of non-sex offenders were chosen from the same prisons. The non-sex offenders were matched to the sex offenders group in term of the length of their sentence. Data was gathered using the self generated questionnaire, Structured Clinical Interview for DSM III-R, SCID and Personality Diagnostic Questionnaires. Results: Religion, education level, history of physical abuse and no history of substance abuse and dependence towards sex offenders. Conclusion: Offenders who only committed sexual offences have some characteristics which differ from other sex offenders who committed non sexual offences as well. Low or no formal education, had history of physical abuse were associated with sex offenders. No history of substance abuse and dependence were associated with no sex offenders.

Keywords: Risk Factors, Sex Offenders

Introduction

Problems of sexual abuse and assault are recognized in almost all countries in the world. It has been reported with different rate of incidence and prevalence depending on the culture of the country. Finkelhor et al¹ reported that the rate of sexual abuse range from 10% to 25%. Ferguson et al² reported 17.3% of sexual in their study and Frank³ reported that reasonable estimate of actual rape is 2 million in one year. Again, there are many factors contribute to the rate of reporting. One of the main factors is social taboo. Bringing the offenders to justice is less important than face saving. Therefore people would rather keep the injustice to themselves and suffer than bringing the perpetrators to justice.
Why is this issue so important to look into? To answer this question, we should look into the impact of it to the community. Once a sexual abuse or assault occurred, the impact will be on the victim, the family members and the society as a whole. Many studies have shown the sequel of the abuse on the victim and family members. A review by Browne and Finkelhor\(^4\) on the long term effects of childhood sexual abuse demonstrated increased risk of sexual disorders, depression, anxiety disorders, auto mutilation, alcohol and substance abuse, eating disorders, feeling self isolation, and stigmatization, deficiencies in self-esteem, anger towards parents and prostitution. A review study by Putnam\(^5\) concluded that childhood sexual abuse is a significant factor for psychopathology especially depression and substance abuse.

It is interesting to look into the characteristics of the sex offenders. However, it is not an easy job as sex offenders are heterogeneous group as they can be pedophilies, rapists, homosexuals and sexual deviants. It is difficult to characterize them as one big group. On top of that they do not volunteer to come forward for treatment because of legal reasons. However, many studies were done looking into their characteristics according to the subgroup. Raymond et al\(^6\) described the commonalities among the sex offenders. They have multiple paraphilias with marked history of abuse and neglected and their problems frequently emerge in adolescent. Lisa and Galynker\(^7\) described about juvenile sex offenders characteristics as they are representatives of all ethnic, racial and socioeconomic classes. However the individual characteristics include lack of assertive and social skills, low academic performance and learning difficulties. Even though there was a study on psychiatric morbidity among the sentenced sex offenders in Malaysia but it is difficult to interpret because the lack of non sex offenders comparison group. Without such comparison group, research on sex offenders may simply reflect non-specific offender characteristics. The area studied is relevant to the clinical practice as it can help us in treating the sex offenders with psychiatric problems and further more it can help the policy makers in making the appropriate and applicable policies for them. A better treatment program can be set up for the benefit of the offenders, which then can prevent recidivism. Therefore, the aim of this study is to determine the socio-demographic characteristics and psychiatric morbidity among the sex offenders.

**Methods**

The study was conducted in the Kajang Prison and Sungai Buloh prison, Selangor, Malaysia. This is a cross sectional study comparing two groups using a combination of survey methodology and personal interviews. The data was collected over a period of six months from January 2004 until June 2004. All convicted sex offenders in respective prisons who are available until July 2004 was included in the study. There were total of 138 sex offenders in both prisons. One hundred and thirty three sex offenders consented to be interviewed and included in the study. Out of five who were excluded, two were denied their participation by the prison authorities, two refused to give consent and one excluded because of language barrier.

A control group of non-sex offenders were chosen from the same prisons. A total number of 110 non-sex offenders were interviewed. The non-sex offenders were matched to the sex offenders group in term of the length of their sentence. This is because in this study we are looking into the
mental status of the respondents and the duration of sentence will affect their mental status.

In this study, the researcher obtained the written consent from the respondents after they were given full explanations about the aim and objectives of the study before they entered the study. The interview will be conducted in private in the respective prisons by the same interviewer (i.e. the candidate) i.e. Kajang Prison and Sungai Buloh Prison. It was held two to three times a week for six months (January until June 2004). In a day four to five prisoners were interviewed in the process of gathering the socio-demographic data and for the assessment of psychiatric status and personality disorders using the diagnostic tools.

Data for socio-demographic was obtained using the self generated questionnaire. The self-generated questionnaires will gather information about age, race, marital status, educational level, occupation, monthly income, family history of psychiatric illness, history of the sexual offence, victim age and the relationship of the victim to the perpetrator. History of previous criminal history also was gathered using this questionnaire.

The Structured Clinical Interview for DSM-III-R (SCID) was originally developed by Spitzer et al. The SCID is a semi structured interview for making the major Axis I DSM-III-R diagnoses. A clinician who has enough clinical experience and knowledge of psychopathology and psychiatric diagnoses to conduct a diagnostic interview without an interview guide should administer it. The SCID is constructed as a clinical interview and starts with questions about the demographic data of the patient. It provides current diagnoses, as well as lifetime diagnoses according to DSM –III-R and DSM-IV. Because of its modular construction, it can be adapted for use in studies where particular diagnoses are not of interest. It has a number of screening questions and the so-called “skipped-outs”.

Personality Diagnostic Questionnaire (PDQ)-4 is a 100 item, self-administered, true/false questionnaires that yield personality diagnoses consistent with the DSM-IV diagnostic criteria for the axis II disorders. It takes approximately 20-30 minutes to complete. The PDQ-4 used in clinical practice and in research projects throughout USA and other part of the world and has been translated in several different languages. For this study, the questionnaire was translated to Malay as most of the respondents are well conversed in Malay. However, the limitation of this is that it is not validated and back translation also was not done.

Permission to run the study among the chosen population was obtained from the Prison Directors. Before each interview session, informed consent was obtained from the subject. The purpose of the study was explained and the need for the result to be discussed with the supervisor of the project was informed. Subjects were not forced to participate but were included on voluntary basis.

The data was analyzed using SPSS version 11.0. To determine the risk factors, logistic regression was used for multivariate analysis. This is to determine the significant risk factors and also to avoid confounding factor. Logistic regression with enter method was used to study the association between all the variables being studied. Due to limited of space, only all the descriptive such as frequency with percentage and odds ratio for significant factors were presented.
Results

The total number of sex offenders was 138 where 133 were participated in this study. Out of five who did not participate in this study, two were denied by prison authorities, two refused to participate and one because of language barrier. Therefore the response rate among the sex offenders was 96.4%. Using multivariate logistic regression analysis, there were association between religion, education level, history of physical abuse and no history of substance abuse and dependence towards sex offenders (Table 1). Those with no formal education and with history of physical abuse were three and 5.5 times more likely involve in sex offenders respectively. Besides that those were present with substance abuse and dependence were unlikely involve in sex offenders (Table 2).

### Table 1. Associated factors with sex offenders, a multivariate analysis

<table>
<thead>
<tr>
<th>Risk factors</th>
<th>P value Multivariate analysis</th>
<th>95% CI Lower</th>
<th>95% CI Upper</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>0.263</td>
<td>0.729</td>
<td>3.208</td>
</tr>
<tr>
<td>Race</td>
<td>0.876</td>
<td>0.345</td>
<td>2.760</td>
</tr>
<tr>
<td>Religion</td>
<td>&lt;0.001</td>
<td>3.190</td>
<td>33.089</td>
</tr>
<tr>
<td>Marital status</td>
<td>0.283</td>
<td>0.420</td>
<td>1.166</td>
</tr>
<tr>
<td>Education group</td>
<td>0.010</td>
<td>1.575</td>
<td>5.454</td>
</tr>
<tr>
<td>Occupation</td>
<td>0.376</td>
<td>0.451</td>
<td>8.229</td>
</tr>
<tr>
<td>History of parental loss</td>
<td>0.510</td>
<td>0.412</td>
<td>1.645</td>
</tr>
<tr>
<td>History of psychiatric illness in family</td>
<td>0.240</td>
<td>0.583</td>
<td>8.441</td>
</tr>
<tr>
<td>History of physical abuse</td>
<td>0.005</td>
<td>0.046</td>
<td>0.557</td>
</tr>
<tr>
<td>History of sexual abuse</td>
<td>0.999</td>
<td>0.000</td>
<td>0.000</td>
</tr>
<tr>
<td>Substance abuse and dependence</td>
<td>&lt;0.001</td>
<td>2.363</td>
<td>11.965</td>
</tr>
<tr>
<td>Alcohol abuse and dependence</td>
<td>0.259</td>
<td>0.325</td>
<td>1.415</td>
</tr>
<tr>
<td>Psychiatric morbidity</td>
<td>0.975</td>
<td>0.472</td>
<td>2.012</td>
</tr>
<tr>
<td>Personality disorder</td>
<td>0.611</td>
<td>0.504</td>
<td>3.351</td>
</tr>
<tr>
<td>Past criminal history</td>
<td>0.638</td>
<td>0.360</td>
<td>1.885</td>
</tr>
</tbody>
</table>

### Table 2. Selected factors that were significantly associated with sex offenders

<table>
<thead>
<tr>
<th>Profile</th>
<th>No. of Sex offenders (%)</th>
<th>No. of Non sex offenders (%)</th>
<th>Odds ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>Religion</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Muslim</td>
<td>117 (88%)</td>
<td>62 (56.4%)</td>
<td>5.7</td>
</tr>
<tr>
<td>Non-Muslim</td>
<td>16 (12%)</td>
<td>48 (43.6%)</td>
<td>3.0</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
No formal education or primary 75 (56.4%) 33 (30%)
Secondary/tertiary 58 (43.6%) 77 (70.0%)

History of physical abuse
Present 32 (24.1%) 6 (5.5%)
Absent 101 (75.9%) 104 (94.5%)

Substance abuse and dependence
Present 26 (19.5%) 54 (49.1%)
Absent 107 (80.5%) 56 (50.9%)

Discussion

The sex offenders’ age are ranging from nineteen years old to eighty-two years old. However majority of cases are aged 26 to 55 years old and there was a decline in number of offenders as they are older. Dickey et al\(^9\) found there is a decline in sexual offences among the offenders as they are getting older. There are few studies to support this finding. Buvat and Lemaire\(^10\) reported that sexual dysfunction, decreased sexual performance and decreased libido were significantly associated with decreasing age. They also reported a decline in testosterone with age primarily after age of forty.

Discussing about the data of the religion of the sex offenders, in this study, we found that majority of the sex offenders were Muslims. This can be explained by looking at the Malaysian population, which comprises of 65.1% of Malays who mostly are Muslims. And among the other group of sex offenders who mainly Indonesians, they were also mostly Muslim. Therefore, the percentage of Muslim in this group is high. Again, the components of religious teaching in Islam made the reporting higher as Muslim unable to accept any premarital sex or any infidelity.

Analysis of level of education among the sex offenders showed that 56.4% has no formal education or primary education compared to the non-sex offenders group which mostly had secondary education. People who committed crime are thought to be a clever person as they can plan well how to commit the crime, therefore in this study we found that among the non-sex offender group, majority has secondary education. While in the sex offender group most of them had no formal or primary education. Studies reported that sex offenders who committed sex offences had low level of education and some had learning difficulties\(^11\). James et al\(^12\) also found that sexual attraction to children by pedophilia was related to poorer intellectual capacity. In the same study, they reported non specific cognitive weakness among the pedophiles and this suggests that people with pedophilia possess a broad cognitive deficit. This could explain the poor ability in planning that leading to being caught by authorities for their offence.

In this study we found a significant difference in parental loss between sex offender and non-sex offender group in univariate analysis however when logistic regression was used in which other confounding factors were taken into account, there was no association found
between the parental loss and the sex offenders. This result is contradicted with the other studies done abroad. Awad et al\(^{13}\), Becker et al\(^{14}\) and William and Mina\(^{11}\) described the family environment of sex offenders as characterized by family conflict, family instability, family dysfunction and exposure to violence. Becker et al\(^{14}\) also described about parenting way which was described as harsh, inconsistent parenting and physical and sexual maltreatment.

The rate of family history with psychiatric illness found to be low in both groups of sex and non-sex offenders i.e. 6.8% and 8.2% respectively. There was no significant difference between the two groups. This is consistent with local study done by Norhashim\(^{15}\). Selvasingam\(^{16}\) also found there is low rate of family history of psychiatric illness among the prisoners in Malaysia.

There was no significant difference found for history of sexual abuse in both groups. There was only two respondents in sex offender group reported that they were sexually abused during childhood. This finding is in contrast with findings in others studies. Majority of studies found that there high rate of history of sexual abuse among the sex offenders. Fazel et al\(^{17}\) reported that 33% of the sex offenders in their study disclosed that they had been sexually abused as children. Another study in treatment center reported 35% of the sex offender had been sexually abuse\(^{18}\). Study of sex offenders in US prison by Greenfield\(^{19}\) reported 28% had history of childhood sexual abuse.

In a culture that sex is a taboo in which the exposure towards sex is very limited these people may be was unable to recognize the act as an offence especially if it occurred about 20 to 25 years ago. This could be one of the reasons why majority of the respondents denied any history of sexual abuse during childhood. However, the researcher found that there is significant difference for physical abuse between the sex and non-sex offenders. This finding is consistent with other studies done. Ryan et al\(^{20}\) found significant history of childhood maltreatment including neglect, physical and sexual abuse in the early lives of the juvenile sex offenders.

In this study we found that 34.6% of sex offender and 30% of the non-sex offenders were diagnosed to have psychiatric diagnosis. Statistical analysis showed there was no significant difference between these two groups. The finding in this study was consistent with other studies. Fazel et al\(^{17}\) also found there was no difference between the sex offender and non-sex offender group. Looking into substance abuse, 19.5% of sex offenders were diagnosed to have abused or dependant on one or more illicit drug and 32.3% abused or dependant on alcohol. In the non-sex offender group, 49.1% were found to have abused or dependant on one or more of illicit drugs and 32.7% were abused or dependant on alcohol.

Comparing the results with studies done abroad, the results in this study is found to be lower. Galli et al\(^{21}\) reported that 50% of the sample diagnosed to have substance abuse and dependence. Peugh and Belenko\(^{22}\) also found two third of sex offenders in their study were substance involved. The lower rate of substance abuse and dependence in this study may be resulted from some limitation in this study. The respondents may be minimized and denied their drugs involvements and the researcher did not have other sources to reconfirm the diagnosis. On the other hand, Peugh and
Belenko in their study used a broader definition for the substance abuse and dependence.

We also could not find any significant difference for personality disorder between sex offenders and non-sex offenders. However, we found that sex offenders with past criminal history shared some of the characteristics with non-sex offender group. We found there is significant difference in personality between the sex offender without past criminal history and sex offender with past criminal history. From this result we may conclude that many sex offenders committed other crime as well. Ryan et al found that 63% of juvenile sex offenders had committed nonsexual delinquent offenses and 28% had committed nonsexual criminal offenses. Righthand and Welch also noted that juvenile sex offenders frequently engaged in non-sexual criminal offences. This result is also consistent with the finding by Mc Elroy et al.

Majority of the sex offenders who were diagnosed to have personality disorders, they were diagnosed to have antisocial personality. Among the sex offenders who were diagnosed to have antisocial personality, majority of them had past criminal history. Studies have reported that there is association between antisocial personality and criminality. Reid described an association between antisocial personality disorder and criminality based on the fact that many behaviors associated with indiscriminate seeking of pleasures and stimulation are illegal and those with antisocial personality disorder are more likely than general population to disregard legality when seeking pleasure and stimulation.

In this study, the results mainly descriptive and described about an association between the variables and does not show any causality. For future study, a prospective study can be done to look into certain factors that can be the cause of being the sex offenders.

**Limitations**

The sex offenders in this study are defined based on legal and criminal definition. As a result, some of the offence can be affected by culture for example; homosexual which is not an offence in some other country but considered as an offence in our country. This may contribute to the difference in the results. This is a study comparing two groups of prisoners. Various factors could have contributed to the psychiatric morbidity among the prisoners. Even though the length of sentence was matched but it was not possible to match variables like age, race, marital status, religion and socioeconomic status. Ideally, with enough resources it will be better if the control group is a matched group.

The respondents in this study only include those who were convicted and were undergoing the sentences. Those who were under remand were not included because several reasons. One main reason was due to legal procedures, as approval from their lawyers was needed. Second factor was due to time factor and limited resources. Those who under remand may be more stressed and in need of psychological support as they were still uncertain of their future, stressful with the legal proceedings and for those of being the first offenders, they had difficulty adjusting to prison life.

The diagnostic interview is based on a retrospective self-report which gives rise to potential problems related to recall biases.
This is a general limitation of studies of this nature. The respondents in this study were generally known to have psychopath personality. There is potential that they might not be telling the truth and minimize the symptoms and problems that the researcher were looking into. It was ideal if the researcher could have interviewed the respondents few times to get the consistency in the history and excluded those with inconsistent history. But because of time factor this could not be done and as a result this may contribute to the difference in findings.

Conclusions

In this study, we found that the offenders who only committed sexual offences have some characteristics which differ from other sex offenders who committed non sexual offences as well. Low or no formal education, had history of physical abuse were associated with sex offenders. No history of substance abuse and dependence were associated with no sex offenders. Although religion was significant, but it might be due to sample selection which from a muslim’s country. Besides that, culture and religion issues were also involved as stated in the discussion.

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The authors would like to thank the Director-General of Health for permission to publish this work and Ministry of Health Malaysia for funding and providing governance for this project. Appreciation is also extended to the Malaysia Department of Prisons for allowing the researchers to conduct this study and not also forgotten to all the participants for their participation and cooperation.

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Cognitive Emotion Regulation Strategies in Women with Major Depressive Disorder

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Abstract

Objective: Disturbance in emotion and cognition is the core feature of major depressive disorder (MDD), which can be expressed as a negative bias in processing information after experiencing stressful events. This examines the use of cognitive emotional regulation strategies by a cohort of adult female patients with a major depressive disorder. Method: A cross-sectional was designed for this study. 40 women with MDD were selected as patient samples and 40 non-clinical females as the control group. Both samples were selected by a purposive method. Pearson correlation between the subscale test and analysis of data was performed by independent-samples t-test.

Result: There were significant differences in cognitive emotion regulation strategies among individuals with MDD compared with the normal samples in these subscales: self-blame (p=0.007), rumination (p=0.001), positive refocusing (p=0.008), refocus on planning (p<0.0001), positive reappraisal (p=0.001), putting into perspective (p=0.035), catastrophizing (p<0.0001) and other-blame (p=0.023). However, in the subscale of acceptance (p=0.549), no significant difference could be observed between patients and the control group. Conclusions: These findings mentioned that poorer cognitive emotional strategies were used by MDD patients in comparison with the health control. Focus on the proper use of cognitive emotion regulation strategies can lead to a better control in stressful situations by patients and can help them to manage their emotional processing.

Keywords: Major Depressive Disorder, Cognitive Strategies, Emotion Regulation

Introduction

Impaired emotional experiences are included in the diagnostic criteria for many mental health disorders in the Diagnostic and Statistical Manual of Mental Disorders like...
Major Depressive Disorder (MDD) that refers to low levels of positive affect (PA), heightened levels of negative affect (NA) and exorbitance guilt. Depression reduces drive, attention and interest in pleasurable activities. Also emotional and cognitive dysfunctions are diagnostic features of MDD. Emotion regulation through cognition or thought is inextricably linked with human life and the degree of emotion regulation can be changed according to significant changes about emotional experiences. Emotional regulation operations might be done consciously or unconsciously and it can act automatically or in a controlled way.

The concept of Cognitive emotion regulation refers to the conscious and cognitive methods that manage emotionally-arousing information for control emotions and coping with problems. Also Cognitive emotion regulation is widely considered as an important issue to mental health. Studies show that emotion dysregulation is associated with a number of psychological problems, such as major depressive ones. Moreover, major depression is a common mental disorder among women so that prevalence of this disorder in women is twice more in men. This greater vulnerability to depression might be the result of differences in socioeconomic status, level of education or specific biological features of women, for example, by hormonal or genetic predisposition.

During emotion regulation, individuals may increase, maintain, or reduce positive and negative emotions. Depression is associated with an overall reduction in both positive and negative emotional responses. Studies show the main problem underlying MDD is the dysregulation of negative emotions, particularly the inability to disengage from negative emotional states. Overall, the ability to recognize appropriate emotional responses to deal with daily events expands neat insights and positive attitudes regarding the occurrence and emotions, and they all play the main roles.

The present study will focus on the extent to which the nine separate cognitive coping strategies are used in response to the experience of life stress in female patients who suffered from MDD, using a specific instrument (CERQ) to measure these cognitive emotional strategies. Understanding the processes underlying the disorder to find an appropriate approach to help these patients for coping with negative life events in future.

**Methods**

A cross-sectional study was conducted for this purpose. Patients were selected from two psychiatric clinics in Tehran from July to November 2012 by purposive method. Explanation about the purpose of this research project and plan was given to each participant individually. Through the semi-structured interview, along with SCID-I and clinical psychiatrist’s assessment, of all 50 patients who had referred to these clinics for the first time and were received the diagnosis of MDD on the basis of the inclusion and exclusion criteria, 40 women were selected as MDD samples of this study while they had not been given any medication or psychotherapy. The demographic form designed to elicit information on three aspects of the participants’ background: age, marital status and level of education. All patients filled out the demographic form; due to similar sex, other variables such as age, marital status and educational level were measured.

The sub-sample of MDD patients consisted of 50 adult females in the age range of 18 to
45 years old (mean age 30.80). Considering the other demographic variables, 64.9% were unmarried, while 32.4% were married, 2.7% was widowed, and no one was divorced. Regarding their educational level, 2.7% indicated to have less than 12 years of education, 24.3% had diploma and 73% had completed university or post graduate degrees.

Patients filled out the cognitive emotion regulation questionnaires (CERQ) at the presence of the researchers. As a result of this questionnaire, 60 women were selected by purposive sampling method initially for the control group. After the clinical interview based on Inclusion and Exclusion criteria, they filled out Symptom Checklist 90 (SCL-90); the multipurpose instrument helps assessment of a wide range of psychological problems and symptoms of psychopathology in different settings. Eventually 40 females were selected as the health control for the study. All samples filled out the demographic form and variables measuring in this group were as the following:

A matched non-clinical group of 60 adults female was obtained in age range of 18 to 47 (mean age 28.54). In this group, 29.7% were married, 70.3% unmarried and no one was divorced or widowed. In educational status, no one had less than 12 years of education, 21.6% had diploma and 78.4% had completed university or post graduate degrees.

Inclusion criteria:

Being diagnosed as MDD was based on the SCID-I which referred to specialized centers before receiving any treatments to answer the questionnaires so that they need to have the literacy ability. Criteria for exclusion from the study: Age less than 18 and more than 60 years old, history of head trauma, neurological disorders (meningitis, encephalitis, etc.), seizure and epilepsy, substance abuse, presence of active psychotic and dissociative symptoms. For the control group, the features included taking axis I and II diagnosis of any disorders, requiring psychiatric treatment and a history of severe psychiatric disorders in first-degree relatives.

**Instruments**

**The Cognitive Emotion Regulation Questionnaire (CERQ)**

In this study, cognitive emotion regulation questionnaire (CERQ) was manipulated to assess cognitive emotion regulation strategies in patients with MDD. Garnefski, Kraaij and Spinhoven (2002) developed a 36-item version of the Cognitive Emotion Regulation. The questionnaire contains nine conceptual scales and the sub-dimension includes: self-blame, acceptance, rumination, positive refocusing, refocusing on planning, putting into perspective, catastrophizing and other-blame. Every scale consists of four items that implicate how people think after the negative or stressful experience, ranging from 1 (never) to 5 (always). Scale scores are obtained by summing up four items in which the minimum was 4 and the maximum was 20. Internal consistencies ranged from 0.68 to 0.83 according to Cronbach’s alphas to be more than 0.80, and test-retest correlations ranged between 0.40 and 0.60, these all indicate moderate stability. In the clinical sample, Cronbach’s alpha ranged from 0.72 to 0.85 and in the non-clinical population reliabilities ranged from 0.76 to 0.86. The questionnaire standardization was performed by Hasani (2011) in Iran while Cronbach's alpha coefficient has been reported from 0.76 to 0.92 and test-retest correlation
coefficient was 0.51 to 0.77 which shows the appropriate stability of the scale\textsuperscript{16}.

**Statistical analysis**

Statistical analyses were conducted with SPSS 18.0 for Windows. The Kolmogorov-Smirnov test was used to evaluate the normal distribution of variables. Moreover, Levene's test was applied for equality of variances. Correlations between subscales were examined using Pearson correlation coefficient. PSS scores were compared between 2 groups by means of independent-samples t-test analysis. Statistical significance was assumed to be at \( p < 0.05 \).

**Results**

Means and standard deviations were calculated in both samples to study the degree to which the nine cognitive emotion regulation strategies were reported by members of MDD sample in comparison with the normal sample. The results are shown in Table 1.

<table>
<thead>
<tr>
<th>Cognitive emotion regulation strategies</th>
<th>Clinical sample ((n=40))</th>
<th>Non-clinical sample ((n=40))</th>
<th>( t )-test for equality of mean</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
<td>M</td>
</tr>
<tr>
<td>Self-blame</td>
<td>12.05</td>
<td>.37</td>
<td>10.84</td>
</tr>
<tr>
<td>Acceptance</td>
<td>13.08</td>
<td>.55</td>
<td>12.40</td>
</tr>
<tr>
<td>Rumination</td>
<td>14.27</td>
<td>.45</td>
<td>12.13</td>
</tr>
<tr>
<td>Positive refocusing</td>
<td>11.16</td>
<td>.65</td>
<td>13.49</td>
</tr>
<tr>
<td>Refocus on planning</td>
<td>12.59</td>
<td>.60</td>
<td>15.84</td>
</tr>
<tr>
<td>Positive reappraisal</td>
<td>12.59</td>
<td>.63</td>
<td>15.46</td>
</tr>
<tr>
<td>Putting into perspective</td>
<td>11.84</td>
<td>.54</td>
<td>13.35</td>
</tr>
<tr>
<td>Catastrophizing</td>
<td>11.92</td>
<td>.47</td>
<td>7.86</td>
</tr>
<tr>
<td>Other-blame</td>
<td>10.57</td>
<td>.45</td>
<td>8.86</td>
</tr>
</tbody>
</table>

* P-value was statistically significant \((p < 0.05)\).

In order to study which of the nine specific cognitive emotion regulation strategies were at the basis of this overall significance, \( t \)-tests were used. Table 1 indicated that significant differences between the MDD population and the non-clinical group were found to report cognitive emotion regulation strategies: self-blame, rumination, positive refocusing, refocus on planning, positive reappraisal, putting into perspective, catastrophizing and other-blame. The result shows that there was not a significant difference in the reporting of acceptance between these two groups.

Table 2 mentioned Pearson inter-correlations between CERQ scales among patients and normal samples. Correlations between subscales ranged between -0.467 (catastrophizing and positive reappraisal) and 0.804 (positive reappraisal and refocus on planning) in normal samples and between -0.339 (self-blame and putting into perspective) and 0.618 (refocus on planning and positive reappraisal) in the MDD samples.
The results, obtained from Table 2 show that in some scales which are moderately correlated in both groups, follow as: 0.588 (positive reappraisal and positive refocusing) in the normal samples and 0.552 in MDD individuals, 0.460 (refocus on planning and positive refocusing) in normal samples and 0.596 in patients, 0.479 (putting into perspective and positive reappraisal) in the normal individuals and 0.549 in MDD samples, and (putting into perspective and refocus on planning) 0.480 in normal group and 0.574 in MDD individuals. These results demonstrated a strong relative correlation between scales.

**Discussion**

In several studies, authors have reported about positive correlation between depression symptoms on one hand, and the use of the cognitive emotion regulation strategies of self-blame, catastrophizing, rumination and other- blame on the other hand\(^5\). In another research on the separate concepts of rumination, the results showed significantly higher rumination scores were associated with severe depression\(^17\).

Beside other studies, evidences showed that rumination affects together with negative cognitive content in creating risk for depression\(^18\-20\).

The present study examined how women with MDD use cognitive emotion regulation strategies while similar results were obtained in recent studies. Self-reported variables show that MDD individuals used the cognitive emotion regulation strategies for self-blame, rumination, catastrophizing and other- blame more than non-patients. Also, they used the positive refocusing; putting into perspective, refocus on planning and positive reappraisal in reverse order. Test-retest correlations suggested that

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**Table 2. Pearson intercorrelations between CERQ subscales for MDD samples (n=40: below diagonal) and non-clinical sample (n=40: above diagonal)**

<table>
<thead>
<tr>
<th></th>
<th>Self-blame</th>
<th>Acceptance</th>
<th>Rumination</th>
<th>Positive refocusing</th>
<th>Refocus on planning</th>
<th>Positive reappraisal</th>
<th>Putting into perspective</th>
<th>Catastrophizing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-blame</td>
<td></td>
<td>.053</td>
<td>.299</td>
<td>-.224</td>
<td>-.151</td>
<td>-.045</td>
<td>-.104</td>
<td>.060</td>
</tr>
<tr>
<td>Acceptance</td>
<td>.118</td>
<td></td>
<td>.304</td>
<td>.114</td>
<td>.032</td>
<td>.103</td>
<td>.035</td>
<td>.387(^*)</td>
</tr>
<tr>
<td>Rumination</td>
<td>.224</td>
<td>.347(^*)</td>
<td></td>
<td>-.083</td>
<td>-.078</td>
<td>-.017</td>
<td>.036</td>
<td>.376(^*)</td>
</tr>
<tr>
<td>Positive refocusing</td>
<td>-.032</td>
<td>-.001</td>
<td>.112</td>
<td></td>
<td>.460(^*)</td>
<td>.588(^**)</td>
<td>.453(^**)</td>
<td>-.301</td>
</tr>
<tr>
<td>Refocus on planning</td>
<td>-.203</td>
<td>.003</td>
<td>-.083</td>
<td>.596(^**)</td>
<td></td>
<td>.804(^**)</td>
<td>.480(^**)</td>
<td>-.439(^**)</td>
</tr>
<tr>
<td>Positive reappraisal</td>
<td>-.046</td>
<td>.048</td>
<td>-.300</td>
<td>.552(^**)</td>
<td>.618(^**)</td>
<td></td>
<td>.479(^**)</td>
<td>-.467(^**)</td>
</tr>
<tr>
<td>Putting into perspective</td>
<td>-.339(^*)</td>
<td>.153</td>
<td>-.174</td>
<td>.444(^**)</td>
<td>.574(^**)</td>
<td>.554(^**)</td>
<td></td>
<td>-.230</td>
</tr>
<tr>
<td>Catastrophizing</td>
<td>.224</td>
<td>.204</td>
<td>.474(^*)</td>
<td>-.201</td>
<td>-.106</td>
<td>-.111</td>
<td>-.247</td>
<td></td>
</tr>
<tr>
<td>Other-blame</td>
<td>.315</td>
<td>.223</td>
<td>.402(^*)</td>
<td>-.114</td>
<td>-.194</td>
<td>-.081</td>
<td>-.088</td>
<td>.364(^*)</td>
</tr>
</tbody>
</table>

\(^*\)p<0.05; \(^**\)p<0.01.
cognitive emotion regulation strategies were relatively stable strategies.

Min and colleagues (2013) suggested that the cognitive emotion regulation strategies of refocus on planning, positive reappraisal, and less rumination contribute to resilience in patients with depression and anxiety disorders21. Cognitive emotion regulation strategies are the way to anticipate emotional problems on a longer term6.

People who identify, control and use the mentioned cognitive emotion regulation strategies, can gain social protection, life satisfaction and more mental health whilst the cause of many emotional disorders is related to some deficits in cognitive control. According to the learned helplessness model, depression is the result of an escape or avoidance deficit after stress and aversive experience that can be uncontrollable22. It can be realized that negative thoughts and wrong beliefs about events and use of dysfunctional coping methods are the results of inability to take the control of negative emotions which can lead to depression. According to conscious concepts, cognitive emotion regulation is carefully related to the concept of cognitive coping23. The study outcomes distinguished the prominent role of cognitive regulation in coping with stressful and negative events.

In fact, the individuals with less proper use of cognitive emotional strategies have lower mental health and life satisfaction. In contrast, the individuals who have more sufficient cognitive emotion of coping strategies to deal with problems and stressful situations can experience a higher level of psychological and mental health.

Future studies should focus on relationships between cognitive emotion regulation and mode of expressing the emotions and behavior of individuals by using self-reported data collection or interviews and specialists' judgments to develop people's consciousness about their cognition and emotion in their stressful life events in order to help them find a solution.

**Conclusion**

Deficits in cognitive emotion regulation skills may lead to the consistency of MDD. Focusing on proper use of cognitive emotion regulation strategies can be an appropriate target in theoretical models, intervention strategies and behavioral intervention.

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The authors would like to express their honorably and truly thanks of the participants for their honest contribution in this study.

**References**


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Caregiving for Epilepsy: Awareness, Knowledge, Attitude and Health-Related Quality of Life of Family Caregivers

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3Medicine & Neurology Department, Hospital Sultanah Nur Zahirah (HSNZ), 20400 Kuala Terengganu, Malaysia
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Abstract

Living with epilepsy is equally demanding for both patients and their caregivers. The caregivers’ tasks are not limited to caring for the patients only but also the need to improve their awareness, knowledge and attitude (AKA) level as lack of understanding has a major impact on health-related quality of life (HRQoL). Little is known about the influence of AKA on family caregivers’ HRQoL. Objective: Therefore, this study aimed to assess and relate the AKA and HRQoL profiles of epilepsy carers. Methods: This prospective, cross-sectional study included a sample of 32 epilepsy family caregivers who were recruited from the Neurology and Paediatric Clinics of Hospital Sultanah Nur Zahirah (HSNZ), Kuala Terengganu. Results: Majority were Muslims (93.8%), married (65.6%), housewives (31.2%), who earning monthly income of not more than RM 1000 (34.4%) and was the patients’ mothers (40.6%). The Total AKA score was generally good (mean=123.4±16.8, median 122.5) with awareness being good, knowledge moderate and attitude positive whereas HRQoL score for Disruptiveness was the highest (good) compared to other domains. There were significantly higher scores for Sexual Functioning (p = 0.039) among Poor AKA group and Pain Management (p = 0.040) among Good AKA. Conclusion: The overall outcomes signified that family caregivers with Good AKA experienced better well-being compared to those with Poor AKA while carrying out their roles as caregivers. Consequently, carers clearly require constant epilepsy education to enhance skill-building in order to understand and keep updates with the disease, thus indirectly sustaining their desired HRQoL status from time to time.

Keywords: Epilepsy, Family Caregivers, Awareness, Knowledge, Attitude, Health-Related Quality of Life
Introduction

Epilepsy is a spectrum of disorders with a range of severities, widely differing seizure types and causes, an array of co-existing conditions and varying impacts on patients and families. Characterized by seizures that are unpredictable in frequency, specific medications and other treatment options could control its occurrence but the impact of the disease goes well beyond it. Living with epilepsy patients exposes one to challenges at home, school, workplace and other outdoor places since epilepsy can impose immense burden on both patients and their family caregivers, causing loss in quality of life (QoL) and daily productivity. Awareness and understanding of epilepsy nature are hence critical to create a better attitude among family caregivers in order to provide a better care for the patients as well as improve their health-related quality of life (HRQoL).

Awareness is an important element for family caregivers of epilepsy which helps offer general perception and picture towards the condition, whereas knowledge is another crucial factor which is associated with the attitudes towards this disease. Many studies have shown that people with less awareness and knowledge about epilepsy demonstrated poorer attitudes. The magnitude of negative attitudes was shown to be aggravated by the presence of misconception of epilepsy which includes the perception of epilepsy as a form of insanity, being untreatable, contagious, and hereditary or a form of mental retardation.

Most research consistently demonstrated that epilepsy patients and their families do not have a comprehensive understanding of the basic information about the illness ranging from how the diagnosis was made, seizure precipitants, types of seizures, the purpose and potential side effects of medications, safety concerns to the risks and potential consequences of seizures. Although some studies have suggested that patients and their families’ attitude regarding epilepsy have become less negative over time, the problems of stigma remain widespread.

In the last two decades, a number of investigations which were associated with the psychological consequences of epilepsy have demonstrated the impact of this disease on patients and caregivers HRQoL. Family caregivers with a good awareness, knowledge and attitude towards this illness had been reported to have better HRQoL scores. Therefore, a systematic study relating to awareness, knowledge and attitudes is crucial to effectively deal with the misconception of epilepsy especially among family caregivers in order to improve their HRQoL. Studies on family caregivers were necessary as the subject have become of upcoming interest to researchers due to the lack of general research conducted among caregivers.

In recent times, a lot of interest have arose on factors associated with epilepsy patients and their caregivers HRQoL, whereby these factors were dissected as follows: 1) clinical variables (seizure frequency and severity, duration of illness, medication side effects), 2) social disadvantages (divorce, unemployment, social stigma) and 3) family circumstances (social support, family caregivers’ character). Accordingly, epilepsy family caregivers were at high risk of anxiety, which could lead to decreased HRQoL. Moreover, the HRQoL of the carer may seriously be affected by the attitudes of their other family members and environment, if the people around were also unaware or uneducated about this illness. Thus, receiving helpful information and
education becomes a critical issue because early perceptions may affect long-term adjustment to the condition. This could play a key role in helping the carers understand and learn about epilepsy more extensively in order to build a positive attitude towards the condition.

This study aimed to evaluate the level of awareness, knowledge, attitude (AKA) and HRQoL among epilepsy family caregivers. The relationship between awareness, knowledge and attitude levels and HRQoL scores were also being compared to investigate how AKA can influence the HRQoL level.

Methods

Ethical approval
Official ethical approval was obtained from the Ministry of Health Research and Ethics Committee Malaysia (MREC) with the reference number, KKM/NIHSEC/800-2/2/2 Jld.3.P13-686. A contact was established with the respective clinic coordinators including the staff nurses and medical assistants to discuss the meeting day, date and time for data collection. The discussion also included the list for suggested potential family caregivers who could be the respondents along with the date and time to meet, study procedures, study duration and requirements needed from the respondents.

Study design and sample selection
This was a prospective, cross sectional study whereby all participants were recruited from Neurology and Paediatric Clinics of Hospital Sultanah Nur Zahirah (HSNZ), Kuala Terengganu, Malaysia. A total of 32 consenting family caregivers agreed to participate in this study. All respondents were among primary family caregivers who accompanied the epilepsy patients during the weekly routine clinic day. For our purpose, the primary family caregivers referred to carers who were involved in a significant amount of time, energy and money over potentially long periods to look after the patients. The requirements for participants included: 1) age of 18 years old and above, 2) capable of completing the questionnaires and 3) can read, write, understand and communicate in Bahasa Melayu or English.

Data collection and study procedure
Data collection was carried out between February to May 2014. The respondents were chosen through the Neurology and Paediatric Clinics patient database list two weeks before study commencement. The list consisted of the names of regular epilepsy patients who attend the treatment in these clinics which always be accompanied by their family caregivers. The caregivers needed for this study were those identified and recommended by the staff nurses.

On the meeting day, the caregivers were initially invited into a designated room for privacy of discussion. They were provided with a thorough explanation on the study purposes and its procedure as written in the Family Caregiver Information Sheet. Written consent form was later signed upon participation agreement by the respondents, who later proceeded to complete the set of questionnaire as follows: 1) Personal Information Form, 2) Malay AKA Epilepsy and 3) Caregiver Quality of Life (CQoL).

Instrument
The Personal Information Form was given to obtain the common demographic characteristics such as gender, age, race, religion, marital status, education level, monthly income, relationship to patient and caregiving information (i.e. duration of caregiving, first diagnosis of patient’s disease and satisfaction in caregiving.
Responses were recorded in the form of multiple-choice answers except for the information of caregiving duration since the patient’s first diagnosis.

Another instrument employed was the Malay AKA Epilepsy. This instrument contained three domains: Awareness, Knowledge and Attitudes which consisted of a total of 20 items. Each response score was range from 0 to 10. The first domain was to detect awareness level which contained five items with total score ranging from 0 to 50, whereby 0-10=very low, 11-20=low, 21-30=moderate, 31-40=high and 41-50=very high. The second domain was to determine knowledge level which contained eight items with total score ranging from 0 to 80, where 0-16=very low, 17-32=low, 33-48=moderate, 49-65=high and 66-80= very high. The last domain measured attitude level which was sampled by four items with total score ranging from 0 to 40, with 0-7=very negative, 8-15=negative, 16-23=indifferent, 24-31=positive and 32-40=very positive. The general AKA level was generated by the summation of these three domains with score ranges from 0-170, whereby 0-33=very poor, 34-67=poor, 68-101=moderate, 102-135=good and 136-170=excellent.

The CQoL questionnaire consisted of a total 35 items assessing Burden (10 items), Disruptiveness (7 items), Positive Adaptation (7 items) and Financial Concerns (3 items) and eight single items of Additional Factors (disruption of sleep, satisfaction with sexual functioning, day-to-day focus, mental strain, informed about illness, protection of patient, management of patient’s pain and family interest in caregiving. Each question is scored on Likert-type response that ranged from 0 (not at all), 1 (a little bit), 2 (somewhat), 3 (quite a bit) and 4 (very much). For all items and domains that measure HRQoL, a higher score represents a better HRQoL. Initially, the CQoL questionnaire has been used in breast cancer population worldwide previously [19] which is an adaptation from Caregiver Quality of Life in Cancer (CQoLC). For this study, we used the Malay version of CQoL which has been preliminarily validated by Lua et al. From our study, the value of Cronbach’s alpha reliability for its total scale was 0.71 while subscale alpha coefficients ranged from 0.40-0.80.

Statistical analysis
The data was analysed using Statistical Package for the Social Science (SPSS) version 17.0 for Windows (SPSS, Inc.). All socio-demographic data was analysed descriptively and presented as frequencies and percentages. Descriptive statistics were used to assess the AKA and HRQoL scores of family caregivers. An initial normality test, carried out utilising AKA scores as a dependent variable, showed that normality requirement was violated (Shapiro-wilk test= p˂0.05; data was positively skewed). Non-parametric tests such as the $\chi^2$ for goodness of fit was employed to test for homogeneity of the proportion of categorical variables, and the Mann–Whitney U test was employed to test between-group score comparisons. For the purpose of these between group comparisons, the patients were regrouped into Good AKA and Poor AKA groups i.e. patients who had a Total AKA score higher than the median were considered to have a good AKA level, whereas those with a Total AKA score equal to or lower than the sample median were considered to have a poor AKA level.

Results

Sociodemographic characteristics
A total of 32 family caregivers participated
in this study. The respondents’ age ranged from 19 to 66 years old with median age of 48.5 years. According to Table 1, female respondents were slightly higher (59.4%) with small number differences compared to males. Most of the carers were married (65.6%), Muslims (93.8%), housewives (31.2%) with highest education level at Sijil Pelajaran Malaysia (SPM) or equivalent to Cambridge O’ level (28.1%). These carers were earning not more than RM 1000 (34.4%), majority were mothers to the patients (40.6%) and were living with their families (53.1%). Significantly greater proportions of the caregivers were within the age group of 39 to 58 years old, already married, were Muslims, with monthly income of less than RM 1000 or none at all, were mothers and were living with their families. In addition, significantly more respondents (65.6%) had cared for the patient for between 1-10 years and admitted being “satisfied” with their caregiving responsibilities.

Table 1. Sociodemographic characteristics of epilepsy family caregivers (n=32).

<table>
<thead>
<tr>
<th>Variable</th>
<th>Frequency (n=32)</th>
<th>Percentage (%)</th>
<th>p value*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (mean ± SD)</td>
<td>46.5 ± 13.4 years</td>
<td></td>
<td></td>
</tr>
<tr>
<td>19-38 years</td>
<td>8</td>
<td>25.0</td>
<td></td>
</tr>
<tr>
<td>39-58 years</td>
<td>18</td>
<td>56.2</td>
<td></td>
</tr>
<tr>
<td>59-78 years</td>
<td>6</td>
<td>18.8</td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>13</td>
<td>40.6</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>19</td>
<td>59.4</td>
<td></td>
</tr>
<tr>
<td>Marital status</td>
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<tr>
<td>Single</td>
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<td>15.6</td>
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<td>Married</td>
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<tr>
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<td>30</td>
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<td>&lt;0.001</td>
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</tr>
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<tr>
<td>Unemployed</td>
<td>2</td>
<td>6.2</td>
<td></td>
</tr>
<tr>
<td>Housewife</td>
<td>10</td>
<td>31.2</td>
<td></td>
</tr>
<tr>
<td>Others</td>
<td>4</td>
<td>12.5</td>
<td></td>
</tr>
<tr>
<td>Education level</td>
<td></td>
<td></td>
<td>0.063</td>
</tr>
<tr>
<td>Primary school</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SRP/PMR or equivalent to lower</td>
<td>8</td>
<td>25.0</td>
<td></td>
</tr>
<tr>
<td>secondary</td>
<td>6</td>
<td>18.8</td>
<td></td>
</tr>
<tr>
<td>SPM or equivalent to Cambridge O’ level</td>
<td>9</td>
<td>28.1</td>
<td></td>
</tr>
<tr>
<td>level</td>
<td>7</td>
<td>21.9</td>
<td></td>
</tr>
<tr>
<td>STPM or equivalent to Cambridge A’ level</td>
<td>3</td>
<td>9.4</td>
<td></td>
</tr>
<tr>
<td>level</td>
<td>3</td>
<td>9.4</td>
<td></td>
</tr>
<tr>
<td>Diploma or equivalent</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Degree or equivalent</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
General AKA and HRQoL profiles

The Total AKA level (Table 2) was considered good with scores ranging between 75 and 155 (mean=123.44±16.82, median 122.50). The Awareness level among family caregivers was particularly rated as good whereas Knowledge and Attitude were considered moderate and positive respectively. The HRQoL subscales scores were as shown in Table 3. The highest domain score was for Disruptiveness (median=3.71) followed by Financial Concerns (median=3.67) and Burden (median= 3.20), while Positive Adaptation (median= 2.43) showed the poorest score among all domains. This reflected that the respondents were doing relatively well in their routine role (with minimal disruptions) compared to other issues involved in their HRQoL. Despite this, their abilities to positively adapt to the situation were the worst.

Table 2. General AKA profile (n=32).

<table>
<thead>
<tr>
<th>Domain</th>
<th>Mean</th>
<th>SD</th>
<th>Median</th>
<th>Range</th>
<th>Interpretation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Awareness</td>
<td>33.13</td>
<td>10.30</td>
<td>30.00</td>
<td>0.00-50.00</td>
<td>Good</td>
</tr>
<tr>
<td>Knowledge</td>
<td>57.81</td>
<td>9.50</td>
<td>60.00</td>
<td>40.00-75.00</td>
<td>Moderate</td>
</tr>
<tr>
<td>Attitudes</td>
<td>32.50</td>
<td>8.61</td>
<td>35.00</td>
<td>10.00-40.00</td>
<td>Positive</td>
</tr>
<tr>
<td>Total AKA</td>
<td>123.44</td>
<td>16.82</td>
<td>122.50</td>
<td>75.00-155.00</td>
<td>Good</td>
</tr>
</tbody>
</table>
Table 3. General HRQoL profile (n=32).

<table>
<thead>
<tr>
<th>Domain</th>
<th>HRQoL</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
</tr>
<tr>
<td>Burden</td>
<td>3.01</td>
</tr>
<tr>
<td>Disruptiveness</td>
<td>3.43</td>
</tr>
<tr>
<td>Positive Adaptation</td>
<td>2.26</td>
</tr>
<tr>
<td>Financial Concerns</td>
<td>3.36</td>
</tr>
</tbody>
</table>

- The score for each domain: 0 = minimum, 4 = maximum.

Comparison of HRQoL family caregivers with different AKA levels

Based on Table 4, there were significant differences in HRQoL level between caregivers with Poor (Total AKA median = ≤122.50) and Good (Total AKA median = >122.50) AKA profiles. The Poor AKA group reported more favourable Positive Adaptation and Family’s Interest as well as significantly better Sexual Functioning ($p = 0.039$). On the other hand, the Good AKA group showed relatively more desirable HRQoL in all other domains, with particular significance for Pain Management ($p = 0.040$). Overall, carers with Good AKA appeared to have better HRQoL status compared to those in Poor AKA group.

Table 4. Differences in HRQoL level based on AKA profile.

<table>
<thead>
<tr>
<th>Domain</th>
<th>Poor AKA Mean Rank (median)</th>
<th>Good AKA Mean Rank (median)</th>
<th>$p$ value*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Burden</td>
<td>15.34 (3.05)</td>
<td>17.66 (3.30)</td>
<td>0.484</td>
</tr>
<tr>
<td>Disruptiveness</td>
<td>13.62 (3.30)</td>
<td>19.38 (3.80)</td>
<td>0.074</td>
</tr>
<tr>
<td>Positive Adaptation</td>
<td>17.00 (2.36)</td>
<td>16.00 (2.43)</td>
<td>0.762</td>
</tr>
<tr>
<td>Financial Concerns</td>
<td>14.59 (3.50)</td>
<td>18.41 (3.83)</td>
<td>0.224</td>
</tr>
<tr>
<td>Sleep Disruption</td>
<td>14.91 (4.00)</td>
<td>18.09 (4.00)</td>
<td>0.225</td>
</tr>
<tr>
<td>Sexual Functioning</td>
<td>19.78 (2.00)</td>
<td>13.22 (0.00)</td>
<td>0.039</td>
</tr>
<tr>
<td>Daily Focus</td>
<td>14.94 (4.00)</td>
<td>18.06 (4.00)</td>
<td>0.192</td>
</tr>
<tr>
<td>Mental Strain</td>
<td>14.56 (4.00)</td>
<td>18.44 (4.00)</td>
<td>0.123</td>
</tr>
<tr>
<td>Disease Information</td>
<td>16.00 (2.00)</td>
<td>17.00 (2.50)</td>
<td>0.755</td>
</tr>
<tr>
<td>Patient Protection</td>
<td>14.88 (4.00)</td>
<td>18.12 (4.00)</td>
<td>0.174</td>
</tr>
</tbody>
</table>
Pain Management 13.81 19.19 0.040
(4.00) (4.00) (4.00)
Family’s Interest 17.09 15.91 0.637
(4.00) (4.00) (4.00)

- *Mann-Whitney U test; p < 0.05 = significant
- Poor AKA = Total AKA median ≤122.50
- Good AKA = Total AKA median > 122.50

Discussion

In a single centre sample of epilepsy family caregivers who were the primary caregivers to the patients, the AKA and HRQoL levels were evaluated and compared. The reasons were because inadequate awareness, improper knowledge and negative attitudes towards epilepsy were notably known to promote social stigma and discrimination, leading to misconception and social misunderstanding which could later affect the overall HRQoL of not only patients but also their family caregivers. In response to the needs in epilepsy caregiving, it is of paramount importance to enhance the AKA levels among carers in order to improve better HRQoL status as well as to allay fears and mistrust about this illness.

With regard to the demographic pattern of our cohort, majority of the caregivers were within the age group of 39-58 years old because the patients were either their children or spouses i.e. this age group commonly consisted of people already married and had children (from our record, patients were mostly between 15-30 years old). As for religion, most respondents were Malay Muslims, thus reflecting the common demographic norm in the Terengganu population. Their rather low monthly income of less than RM 1000 (or none) could be because they were either self-employed or were not working at all (especially the housewives). Mothers were primarily the carers, understandably because most patients were actually teenagers who were still under parental care and support, indirectly too explaining their living arrangement with their families. In spite of the general burden in caregiving, almost two-third of the carers admitted being satisfied in carrying out their duties, this was probably due to their natural contentment in taking care of their loved ones. It has been shown that caring for the sick (although stressful) could still be “rewarding” in terms of spiritual fulfilment as a previous study among HIV/AIDS patients reported that several informants felt more enthusiastic to manage their caregiving errands. Furthermore, most of our caregivers had only been entrusted with the responsibilities for less than 10 years, because it was possible that negative issues may have not yet emerged or imposed their impacts. Besides that, their strong religious belief as Muslims (majority of respondents) could also be a positive contributing factor i.e. to accept whatever fate delivered by God (termed as “takdir” in Malay language).

The findings presented in this study, contrary to other investigations in Malaysia indicated that the overall AKA level of epilepsy carers in Kuala Terengganu was actually good, which was relatively better than what was reported in another AKA study of epilepsy. Nonetheless in the latter, the focus was mainly on public perspectives rather than from direct family carers. Despite good awareness level among our caregivers, their knowledge level however was still moderate and lack of consistent and accurate information about
this clinical condition seemed to be the main determinant in shaping their apparently still limited understanding.\textsuperscript{25} Moreover, false beliefs may still exist, which could have easily been propagated from one to another within the same close-knit community, thus worsening the matter.\textsuperscript{[18]} Importantly, a recent study have indicated that the Malaysian education system’s attempt to improve healthcare AKA by integrating health-related subjects into the standard curriculum was indeed very proactive, but unfortunately, no emphasis was given on more specific topics such as epilepsy.\textsuperscript{26} On the other hand, attitudes towards this disease were encouragingly positive and this favourable outcome may have stemmed from the familiarity of this disorder among the people or communities previously affected by similar problem. This phenomenon has been identified in a similar research whereby the more exposed people were to a certain condition like epilepsy, the better their attitude seemed to be towards that disorder.\textsuperscript{10}

With respect to general HRQoL status, it was clear that our carers were negatively affected by Positive Adaptation since it recorded as the lowest score of all domains. Consistent with our findings, several investigations have reported that most caregivers (particularly the parents) were struggling with great difficulties to admit and accept the patients’ diagnosis.\textsuperscript{27} They were also very concerned about the unpredictable nature of epilepsy, prognosis and the side effects of anti-convulsants as well as the “epilepsy” label itself. All these issues may have imposed anxiety, uncertainties and ultimately problems in attempting to positively adapt to the challenging situation.

As expected, differences in HRQoL profiles could be seen between the Poor AKA and Good AKA groups. Carers with Good AKA consistently scored higher for almost all domains particularly in Pain Management (this particular question asked about their burden in managing the pain of their loved ones). Pain Management was included as one aspect of caregiving involving both physical and emotional demands, in which family caregivers became particularly central to home-care management efforts, hence significantly affecting their HRQoL.\textsuperscript{28,29} For example in our Good AKA group, majority were mothers who usually cope well with stressful and ill conditions related to their loved ones especially children. These abilities were naturally derived from their previous experience of child-caring, thus the current epilepsy-caring could not have significantly impacted on their daily life routines. In contrast, the Poor AKA respondents were perhaps unable to juggle their routines due to being less aware and less knowledgeable, which later resulted in comparatively worse Pain Management. Although the Good AKA group experienced better HRQoL, the Poor AKA unexpectedly also did well in Sexual Functioning which seemed to suggest that the caregiving duties have not negatively affected this aspect of HRQoL.

Nonetheless, our study utilised a cross sectional design which relied upon only a single public hospital enrolment resulting in rather limited sample size which inevitably created bias for generalisation. As this study was based on convenience sampling, other “out-of-control” external confounders (e.g. education level, duration of care) could have also distorted the results, besides recruiting respondents from a place largely dominated by Malay Muslims. Again, the already small sample did not permit more reliable statistical tests such as regression analysis or ANCOVA to be conducted.
Conclusion

It can be concluded that our findings exhibited important outcomes that reinforced the relationship between AKA and HRQoL among epilepsy carers. Despite the limitations, this study somehow managed to reveal that AKA level could be influential to the HRQoL status of family caregivers, with increased AKA being favourable to better HRQoL. Consequently, caregivers should have access to constant epilepsy education as much as possible, participate in research and be active advocates for improvements in caregiving and their HRQoL. Continuously-enhanced AKA and HRQoL status would not only mean that their lives are more adaptable and bearable but the caregiving process could also be carried out at its optimum all in the patients’ best interest. Therefore, future research should attempt to develop structured and comprehensive epilepsy educational programmes in the midst of providing the best therapies coupled with optimal caregiving quality.

Acknowledgement

We wish to thank the Director-General of Health, Malaysia and the Ministry of Health Medical Research and Ethics Committee (MREC) for permission to conduct our study and subsequently the publication of this paper. We are greatly indebted to the Hospital Director and staff of Hospital Sultanah Nur Zahirah (HSNZ) for their support and assistance in ensuring the success of this study, not forgetting the full cooperation from all participants and individuals for their invaluable support towards this study.

Conflict of interest

No competing financial interest exists.

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Health-Related Quality of Life of Patients with Chronic Depression in Malaysia

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3School of Pharmaceutical Sciences, University Science Malaysia, Penang, Malaysia

Abstract

Objective: To evaluate the health-related quality of life (HRQOL) of patients with chronic depression. Methods: The study involved patients with chronic depression being followed-up at an outpatient clinic at a local hospital in Malaysia. HRQOL was assessed using the Sheehan Disability Scale (SDS); while symptom severity was assessed using the Montgomery-Asberg Depression Rating Scale (MADRS). Results: 104 patients of Malay, Chinese and Indian ethnic groups met the selection criteria. Mean total SDS and MADRS scores was 9.36 ± 7.92 and 13.99 ± 11.58 respectively. There were no significant differences of HRQOL scores between the different ethnicities and between males and females. Symptom severity significantly influenced total and component HRQOL scores. Conclusions: The HRQOL of patients with chronic depression was found to be significantly influenced by symptom severity. Data obtained in this study can be used in the design and implementation of therapeutic and preventive interventions.

Keywords: Health-Related Quality of Life, Chronic Depression, Predictors

Introduction

Traditional outcome measures such as symptom reduction, while important, seem to exaggerate therapeutic goals; while other equally important outcomes such as patients’ needs and concerns, which include material living conditions, negative physical, psychological and social side effects; have been relegated to the background or completely ignored. Health-related quality of life (HRQOL) has been viewed as the patient’s perspective on what they have (such as access to resources and opportunities), how they are doing and how they feel about their life circumstances1. Hence HRQOL research introduces a more humanitarian approach and offers a more comprehensive evaluation as to how the patient is actually responding to the drugs, as well as the impact of the disease2-6. This approach then helps improve the quality of care provided to these patients7.
Patients with depression are associated with a high level of functional disability, increased disability days, and amplified utilization of outpatient medical services. Thus far, the majority of studies on the HRQOL of patients with depression have focused on Western populations. However given that differences in economic status, ethnicity, culture and the social psychology of patients could influence their HRQOL, it would seem that these findings would have limited generalizability to the Asian population. In Malaysia, not many trials have sought to investigate the effect of depression on HRQOL. To our knowledge, only one such study was conducted 10 years ago among patients with schizophrenia, bipolar and depressive disorders in remission. There has been no study so far that focused on chronic patients with unipolar depression. Thus the aim of this study was to obtain and present data regarding the HRQOL of patients with chronic unipolar depression in Malaysia.

Methods

This study is part of the Pharmacy-Managed Adherence Program (PAPD) study, a 6-month randomized prospective study designed to investigate the effect of the program on adherence levels. The study involved patients with chronic depression being followed-up at the outpatient clinic of the psychiatric department of a hospital in Malaysia. Results reported here represent baseline data from the study.

All patients who were diagnosed with major depressive disorder (MDD) according to the DSM-IV or ICD-10, regardless of severity, and who had been on antidepressants for a minimum of 6 months were included in the study. A sample size of 160 was required, calculated using the formula suggested by Dawson and Trap. The following patients were excluded from the study: patients with a comorbid diagnosis of schizophrenia or bipolar disorder during the study period; patients less than 18 years of age; patients who were pregnant or breast-feeding; patients with current suicidal ideation or with a terminal illness; patients with dementia, cognitive disabilities, mental retardation, Alzheimer’s or Parkinson’s; patients who did not understand, speak or read English or Bahasa Malaysia (BM); and patients who were unable to complete the self-administered questionnaire with minimal assistance from the psychiatric staff.

Patients who agreed to participate and who signed informed consent forms were asked to complete the Sheehan Disability Scale (SDS) which was used to measure patient’s HRQOL. Patients rated the extent to which the 3 domains, namely ‘Work’, ‘Family’ and ‘Social’ were impaired by his/her symptoms on a 10-point visual analogue scale, which ranged from 'Not at all (0)' through 'Mildly (1-3)', 'Moderately (4-6)' and 'Markedly (7-9)' to 'Extremely (10)'. The 3 items were summed into a single dimensional measure of global functional impairment from 0 to 30, where 0 indicated the patient was unimpaired and had good HRQOL; and 30 indicated the patient was highly impaired or had poorest HRQOL. Symptom severity was assessed using the Montgomery-Asberg Depression Rating Scale (MADRS). Demographic data as well as medical and psychiatric history was also obtained. This study was approved by the Medical Research Ethics Committee of the Ministry of Health, Malaysia.

In analysing the differences between gender and ethnicities, independent t-test or its corresponding Mann Whitney test was used to analyse continuous data, while the Chi-
squared goodness-of-fit test was used for categorical data. Multiple linear regression was employed to examine predictors of HRQOL. Variance Inflation Factor (VIF) values were inspected for the possibility of multicollinearity, with results higher than 10 being considered as indicative of this problem; and independent variables found to be significant predictors were checked for interactions. The a priori level of significance was 0.05, and all analyses were performed using the SPSS 18.0 statistical software.

**Results**

104 patients, who fulfilled the inclusion criteria, participated in the study. The majority were female, married, of Malay ethnicity; and were between 40-49 years of age (29.8%). Most patients had been receiving psychiatric care for a period of 10 years or more (17.3%). The maximum amount of time that a patient had been in psychiatric care was approximately 21 years, while the minimum amount of time was 7 months (3 patients). Mean total MADRS score was 13.99 ± 11.58. Of the total unemployed patients, 75.5% were women. All patients were on only one antidepressant except for two patients who were on two antidepressants. All patients were on once daily dosing [Table 1].

**Table 1.** Demographic characteristics of study participants

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Malay (n=44)</th>
<th>Chinese (n=26)</th>
<th>Indian (n=34)</th>
<th>Total (n=104)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>18 (17.3)</td>
<td>8 (7.7)</td>
<td>12 (11.5)</td>
<td>38 (36.5)</td>
</tr>
<tr>
<td>Female</td>
<td>26 (25.0)</td>
<td>18 (17.3)</td>
<td>22 (21.2)</td>
<td>66 (63.5)</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>9 (8.7)</td>
<td>4 (3.8)</td>
<td>8 (7.7)</td>
<td>21 (20.2)</td>
</tr>
<tr>
<td>Married</td>
<td>31 (29.8)</td>
<td>22 (21.2)</td>
<td>21 (20.2)</td>
<td>74 (71.2)</td>
</tr>
<tr>
<td>Divorced</td>
<td>4 (3.8)</td>
<td>0 (0.0)</td>
<td>1 (1.0)</td>
<td>5 (4.8)</td>
</tr>
<tr>
<td>Widowed</td>
<td>0 (0.0)</td>
<td>0 (0.0)</td>
<td>4 (3.8)</td>
<td>4 (3.8)</td>
</tr>
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<td>Education</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary</td>
<td>6 (5.8)</td>
<td>6 (5.8)</td>
<td>4 (3.8)</td>
<td>16 (15.4)</td>
</tr>
<tr>
<td>Secondary</td>
<td>24 (23.1)</td>
<td>16 (15.4)</td>
<td>24 (23.1)</td>
<td>64 (61.5)</td>
</tr>
<tr>
<td>Tertiary</td>
<td>14 (13.5)</td>
<td>4 (3.8)</td>
<td>6 (5.8)</td>
<td>24 (23.1)</td>
</tr>
<tr>
<td>MADRS symptom severity</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Recovery (0-6)</td>
<td>16 (15.4)</td>
<td>9 (8.7)</td>
<td>14 (13.5)</td>
<td>38 (36.5)</td>
</tr>
<tr>
<td>Mild (7-19)</td>
<td>16 (15.4)</td>
<td>10 (9.6)</td>
<td>8 (7.7)</td>
<td>35 (33.7)</td>
</tr>
<tr>
<td>Moderate (20-34)</td>
<td>10 (9.6)</td>
<td>7 (6.7)</td>
<td>7 (6.7)</td>
<td>24 (23.1)</td>
</tr>
<tr>
<td>Severe (≥ 35)</td>
<td>2 (1.9)</td>
<td>0 (0.0)</td>
<td>5 (4.8)</td>
<td>7 (6.7)</td>
</tr>
<tr>
<td>Number of suicide attempts</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>35 (33.7)</td>
<td>22 (21.2)</td>
<td>26 (25.0)</td>
<td>83 (79.8)</td>
</tr>
<tr>
<td>1</td>
<td>7 (6.7)</td>
<td>2 (1.9)</td>
<td>3 (2.9)</td>
<td>12 (11.3)</td>
</tr>
<tr>
<td>2</td>
<td>2 (1.9)</td>
<td>1 (1.0)</td>
<td>5 (4.8)</td>
<td>8 (7.7)</td>
</tr>
<tr>
<td>3</td>
<td>0 (0.0)</td>
<td>1 (1.0)</td>
<td>0 (0.0)</td>
<td>1 (1.0)</td>
</tr>
<tr>
<td>Number of emergency room visits</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>40 (38.5)</td>
<td>25 (24.0)</td>
<td>27 (26.0)</td>
<td>92 (88.5)</td>
</tr>
<tr>
<td>1</td>
<td>3 (2.9)</td>
<td>1 (1.0)</td>
<td>7 (6.7)</td>
<td>11 (10.6)</td>
</tr>
<tr>
<td>2</td>
<td>1 (1.0)</td>
<td>0 (0.0)</td>
<td>0 (0.0)</td>
<td>1 (1.0)</td>
</tr>
</tbody>
</table>
Number of psychiatric hospitalization
\[ \begin{array}{c|cccc}
0 & 36 (34.6) & 21 (20.2) & 24 (23.1) & 81 (77.9) \\
1 & 7 (6.7) & 5 (4.8) & 8 (7.7) & 20 (19.2) \\
2 & 1 (1.0) & 0 (0.0) & 2 (1.9) & 3 (2.9)
\end{array} \]

Attending counselling sessions
\[ \begin{array}{c|cccc}
Yes & 10 (9.6) & 2 (1.9) & 5 (4.8) & 17 (16.3) \\
No & 34 (32.7) & 24 (23.1) & 29 (27.9) & 87 (83.7)
\end{array} \]

Employed
\[ \begin{array}{c|cccc}
Yes & 27 (26.0) & 12 (11.5) & 16 (15.4) & 55 (52.9) \\
No & 17 (16.3) & 14 (13.5) & 18 (17.3) & 49 (47.1)
\end{array} \]

Comorbid psychiatric disorders
\[ \begin{array}{c|cccc}
Anxiety & 16 (15.4) & 7 (6.7) & 5 (4.8) & 28 (26.9) \\
Obsessive compulsive & 1 (1.0) & 0 (0.0) & 1 (1.0) & 2 (1.92) \\
Panic & 1 (1.0) & 0 (0.0) & 0 (0.0) & 1 (0.96) \\
Phobia & 1 (1.0) & 0 (0.0) & 0 (0.0) & 1 (0.96) \\
PTSD & 0 (0.0) & 1 (1.0) & 0 (0.0) & 1 (0.96)
\end{array} \]

Prescribed antidepressant
\[ \begin{array}{c|cccc}
Fluvoxamine & 17 (16.3) & 2 (1.9) & 17 (16.3) & 36 (34.6) \\
Sertraline & 9 (8.7) & 8 (7.7) & 7 (6.7) & 24 (23.1) \\
Escitalopram & 6 (5.8) & 6 (5.8) & 6 (5.8) & 18 (17.3) \\
Venlafaxine & 6 (5.8) & 2 (1.9) & 1 (1.0) & 9 (8.7) \\
Mirtazapine & 1 (1.0) & 6 (5.8) & 1 (1.0) & 8 (7.7) \\
Fluoxetine & 3 (2.9) & 2 (1.9) & 1 (1.0) & 6 (5.8) \\
Duloxetine & 0 (0.0) & 2 (1.9) & 0 (0.0) & 2 (1.9) \\
Dothiepin & 1 (1.0) & 0 (0.0) & 1 (1.0) & 2 (1.9) \\
Amitriptyline & 1(1.0) & 0 (0.0) & 0 (0.0) & 1 (0.0)
\end{array} \]

*Percentage is over total number of patients
†PTSD = Post-traumatic Stress Disorder

Mean SDS score was 9.36 ± 7.92. 57.7% of patients had a total score of less than ‘10’, followed by 35.6% with a score between ‘11-20’. Approximately 6% of patients had scores between ‘21-30’. There were no significant differences in total SDS scores between males and females, and between the different ethnicities.

Component analysis revealed that the majority of patients had scores of ‘0’ on all three components. This was followed by the midline range and the full score of ‘10’, especially for the ‘Social’ and ‘Family’ components. In terms of ‘Work’ however, most patients congregated between the ‘0-3’ range. Only four (3.8%) patients had scores more than ‘6’, reflecting markedly impaired, on all three components [Figure 1]. Analysis of results by ethnicity and gender revealed no significant differences. Using the definition adopted by Demytyttenaere et al in their study where ‘Recovery’ was defined as a score of less than ‘4’ on all three components on the SDS scale, 43 (41.3%) patients showed recovery.
Figure 1. Scores on SDS Components for all Patients Studied (n=104)

Stepwise regression analysis revealed that total SDS scores was primarily predicted by symptom severity, as reflected in MADRS scores [Table 2]. Regression analysis of factors that predict the three components of the SDS revealed that all three components were also influenced by symptom severity [Table 3].

Table 2. Stepwise regression analysis for factors associated with total HRQOL in 104 patients with chronic depression

<table>
<thead>
<tr>
<th>Model</th>
<th>SLR*</th>
<th>P value</th>
<th>MLR†</th>
<th>t-stat</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>b‡ (95% CI)</td>
<td>Adj.b§ (95% CI)</td>
<td>t-stat</td>
<td></td>
<td></td>
</tr>
<tr>
<td>_age (year)</td>
<td>-0.11 (-0.24, 0.02)</td>
<td>0.09</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>_length of time in psychiatric care (months)</td>
<td>-0.01 (-0.04, 0.02)</td>
<td>0.55</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>_MADRS score</td>
<td>0.39 (0.27, 0.50)</td>
<td>&lt;0.001</td>
<td>0.44 (0.33, 0.55)</td>
<td>8.09</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>_Education</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary</td>
<td>1.0</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Secondary</td>
<td>2.33 (-8.27, 5.48)</td>
<td>0.15</td>
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<td></td>
</tr>
<tr>
<td>Tertiary</td>
<td>-3.28 (-6.90, 0.34)</td>
<td>0.08</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>_Race</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Malay</td>
<td>1.0</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chinese</td>
<td>0.14 (-3.44, 3.72)</td>
<td>0.94</td>
<td></td>
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<td></td>
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<tr>
<td>Indian</td>
<td>-0.66 (-3.96, 2.64)</td>
<td>0.69</td>
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<tr>
<td>_Relationship status</td>
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<td></td>
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<td></td>
</tr>
<tr>
<td>Malay</td>
<td>1.0</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Status</td>
<td>Regression Coefficient</td>
<td>Adjusted Coefficient</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>----------</td>
<td>------------------------</td>
<td>----------------------</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>-1.66 (-5.06, 1.75)</td>
<td>0.34</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>1.31 (-5.93, 8.55)</td>
<td>0.72</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Divorced</td>
<td>-6.61 (-14.56, 1.34)</td>
<td>0.10</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Widow</td>
<td>1.34</td>
<td></td>
<td></td>
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</tbody>
</table>

Employment status

<table>
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<tr>
<th>Status</th>
<th>Regression Coefficient</th>
<th>Adjusted Coefficient</th>
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</thead>
<tbody>
<tr>
<td>Yes</td>
<td>0.94 (-2.16, 4.04)</td>
<td>0.55</td>
</tr>
<tr>
<td>No</td>
<td>1.0</td>
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</table>

*Simple linear regression
†Multiple linear regression ($R^2 = 0.41$; The model reasonably fits well; Model assumptions are met; There is no interaction between independent variables, and no multicollinearity problem)
‡Crude regression coefficient
§Adjusted regression coefficient
Table 3. Stepwise regression analysis for factors associated with SDS Components in 104 patients with chronic depression

<table>
<thead>
<tr>
<th>Model</th>
<th>Social Component</th>
<th>Family Component</th>
<th>Work Component</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>SLR*</td>
<td>MLR†</td>
<td>SLR*</td>
</tr>
<tr>
<td></td>
<td>b (95% CI)</td>
<td>P value</td>
<td>Adj.b (95% CI)</td>
</tr>
<tr>
<td>Age (year)</td>
<td>-0.02 (-0.08, 0.04)</td>
<td>0.14</td>
<td>-0.04 (-0.10, 0.01)</td>
</tr>
<tr>
<td>Length of time in psychiatric care (months)</td>
<td>-0.01 (-0.02, 0.01)</td>
<td>0.48</td>
<td>-0.00 (-0.02, 0.01)</td>
</tr>
<tr>
<td>MADRS score</td>
<td>0.17 (0.12, 0.22)</td>
<td>&lt;0.001</td>
<td>0.18 (0.13, 0.23)</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary</td>
<td>1.43 (0.05, 2.80)</td>
<td>0.04</td>
<td>1.21 (-0.20, 2.61)</td>
</tr>
<tr>
<td>Secondary</td>
<td>-1.89 (-3.46, -0.32)</td>
<td>0.02</td>
<td>-1.50 (-3.11, 0.12)</td>
</tr>
<tr>
<td>Race</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Malay</td>
<td>0.21 (-1.37, 1.78)</td>
<td>0.80</td>
<td>0.06 (-1.53, 1.66)</td>
</tr>
<tr>
<td>Chinese</td>
<td>-0.32 (-1.13, 1.77)</td>
<td>0.66</td>
<td>-0.41 (-1.88, 1.07)</td>
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<td>Relationship status</td>
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<tr>
<td>Single</td>
<td>-0.03 (-1.54, 1.47)</td>
<td>0.97</td>
<td>-0.09 (-1.62, 1.43)</td>
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<tr>
<td>Married</td>
<td>-1.03 (-4.20, 2.15)</td>
<td>0.52</td>
<td>0.14 (-3.09, 3.37)</td>
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<tr>
<td>Divorced</td>
<td>-1.90 (-5.42, 1.62)</td>
<td>0.29</td>
<td>-2.93 (-6.48, 0.62)</td>
</tr>
<tr>
<td>Widow</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employment status</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Yes</td>
<td>-1.53 (-2.86, -0.20)</td>
<td>0.02</td>
<td>-0.45 (-1.84, 0.93)</td>
</tr>
<tr>
<td>No</td>
<td>1</td>
<td></td>
<td>1</td>
</tr>
</tbody>
</table>

*Simple linear regression
†Multiple linear regression [R² = 0.39 (Family), 0.36 (Social) and 0.35 (Work); The model reasonably fits well; Model assumptions are met; There is no interaction between independent variables, and no multicollinearity]
‡Crude regression coefficient
§Adjusted regression coefficient
Discussion

The majority of patients had mild disability and this is consistent with the results showing the majority of patients were in the ‘Recovery’ phase with regard to symptom severity. Multiple regression revealed that symptom severity was a predictor of HRQOL across the board, and this has been noted in several studies\(^{24-28}\). Another interesting and important point to note is that when analysing the components of the SDS as reflected in Figure 1, a pattern was observed where most patients either selected ‘0’, ‘5’ or ‘10’. This was very different from that observed in a study by Demyttenaere et al\(^{29}\) where most patients selected between 5-8 on all three subscales. What this shows is that the majority of the patients in the study have both extreme and neutral behaviours, with extreme behaviours selecting scores at either end of the spectrum i.e. ‘0’ or ‘10’; while neutral patients select the mid-point of ‘5’. This could have somewhat compromised the results.

It is important to determine what factors really influence HRQOL and how they affect patient’s HRQOL as these factors can then be modified, to improve HRQOL in such patients, and can be used in the planning of treatment or care of patients accordingly\(^{20}\). Indeed HRQOL should be regarded not as a one dimensional outcome influenced only by a handful of factors, but instead a powerful interplay between several factors that are perceived to be important\(^{24,30}\).

The limitations of this study are the small sample size and the fact that most patients were in the recovery phase, which might limit the generalizability of the results obtained. A more comprehensive study involving a larger sample of patients with various levels of depression severity should thus be undertaken to confirm the predictive factors of HRQOL in the Malaysian setting.

Conclusion

Symptom severity significantly influenced the HRQOL of patients. Data obtained on HRQOL characteristics as well as its predictive factors can be used by members of the psychiatric unit such as psychiatrists, nurses, counsellors and pharmacists; in the design and implementation of therapeutic and preventive interventions.

Acknowledgement

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References


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**Email:** sabyj@hotmail.com
CASE REPORT

Psychotic Manifestation in a Patient with Wolfram Syndrome (DIDMOAD)

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Abstract

Wolfram syndrome (WFS) is a rare neurodegenerative disorder which is characterized by presentation of diabetes insipidus, juvenile diabetes mellitus, optic atrophy and deafness. We describe a case of WFS with presentation of psychosis. A 17-year-old female presented with psychiatric manifestations, namely inappropriate behaviour and second person auditory hallucination since the age of 16 years. The patient was diagnosed with type 1 diabetes mellitus at the age of 10 years old and subsequently progressive hearing and visual loss a year later. Her ophthalmic evaluation revealed total blindness due to optic atrophy. However she did not have renal dysfunction and diabetes insipidus which are also features of the syndrome. There is scarce literature to describe on psychiatric presentation in WFS. In the past, the psychiatric manifestation which was reported most of times was mood and suicidal behaviour. Hardly any article reported about psychosis (hallucination). We believe, her psychiatric manifestations were related to sensory deprivation due to blindness and deafness caused by the progression of WFS.

Keywords: Wolfram Syndrome, Diabetes Mellitus, Optic Atrophy, Psychiatric Manifestation

Introduction

The Wolfram syndrome is a rare, complex, hereditary, progressive neurodegenerative genetic disorder which was first described by Wolfram and Wagener in 1983.¹ It is characterized by non-inflammatory atrophic changes in the brain and in pancreatic islets resulting in diabetes insipidus, diabetes mellitus, optic atrophy and deafness. The syndrome is denoted by the acronym of
DIDMOAD which elaborates its medical presentations.\(^2,3\)

The underlying pathogenesis of the syndrome is not well known, however genetic inheritance through autosomal recessive is identified as a strong etiological explanation. The prevalence of WFS in general population is rare with the estimation of 1 per 770,000 population.\(^4\) Generally there is equal gender distribution between males and females. Parental consanguinity has been noted to be common among WFS cases and it is estimated happened 1 in 350 people carrying the genes of Wolfram Syndrome.\(^4\)

In literature, patients with Wolfram Syndrome have been reported with psychiatric presentations but mainly mood symptoms and depression not psychosis. This paper describes the presentation of psychotic symptoms by a patient with Wolfram Syndrome.

**Case Report**

A 17-year-old female was referred to the Department of Psychiatry and Mental Health, Hospital Tunku Ampuan Afzan Kuantan for psychiatric evaluation. She presented with abnormal behaviour and having auditory hallucination since the age of 16. She was diagnosed to have diabetes mellitus at the age of 10 years old and currently on regular insulin injection. She developed progressive hearing and visual loss and bilateral optic atrophy at the age of 12 years.

The abnormal behaviour consisted of laughing and crying for no apparent reasons. She repeatedly complained of being disturbed by someone’s voices near her though she was alone at that time. She would respond back by saying ‘please do not disturb me’ according to her mother. Though the communication was difficult it was clearly presence of second person auditory hallucinations through hearing aid.

The parents described her to be irritable and tended to shout inappropriately. She was socially withdrawn and most of the time she would isolate herself in a room. She neglected her personal hygiene and her speech was irrelevant at times.

She was born of consanguineous marriage. Her parents are first degree cousins. Two out of her siblings were also diagnosed to have WFS. The elder was diagnosed at the age of 10 years and another sister at the age of 13 years. Otherwise, there was no family history of psychiatric illness.

Mental state examination revealed poor rapport and labile mood. She kept on knocking her hands on a table. She was making in comprehensible sounds and kept on saying “go away”. Sometimes she smiled inappropriately and there was loosening of association in her speech. When she was asked about perceptual disturbance, she admitted of having visual and auditory hallucination since a few months back. She required a hearing aid device to help to enhance her hearing.

Bilateral papillary atrophy was found in optic fundoscopic examination. Her audiometric examination revealed of unilateral neurosensory deafness. She was diagnosed to have psychotic symptoms due to underlying Wolfram clinical manifestation. She was started on tablet Risperidone 0.5 mg daily and she responded well. Her behavioural abnormalities and psychosis resolved immediately within few weeks. As for 9 months from her referral to psychiatrist, she was well behaved without any abnormal behaviour and noted to be
fairly manageable. MRI of the patient showed no obvious abnormal findings.

**Discussion**

We present here a classical case of Wolfram syndrome with psychotic symptoms. She has consanguineous parents with two other siblings were also diagnosed with Wolfram syndrome. This patient was presented with diabetes mellitus associated with optic atrophy in the first decade; sensorineural deafness and blindness in the second decade. However renal tract abnormalities and multiple neurological abnormalities such as cerebellar ataxia, myoclonus, and psychiatric illness which commonly reported in their fourth decade are not present in this patient.\(^5\) In this case the psychosis presentation is rather slight early unlike what was been reported in literature.

In our literature search, there are not many literatures mentioning about psychiatric presentation in WFS except very few case reports which tried to identify the cause of psychotic symptoms and the psychiatric symptoms were mainly reported as mood fluctuations.\(^5\) It has been reported that patients with Wolfram syndrome were more likely to have mood disorders such depression, mood swings and also suicidal tendency.\(^5,\,6\) Mood swings in Wolfram syndrome is said may also be caused by hypoglycaemia syndrome. Further search specifically on the aspect of psychosis or hallucination is even scarce. Although there are not many literatures to elaborate on the etiological cause of psychiatric presentations in Wolfram syndrome, it has been reported minimally in a few case reports. In this case we regard her auditory hallucination was resulted from sensorial deprivation. In literature not related to WFS, perceptual disturbances such as auditory and visual hallucinations could be influenced by environmental conditions such as sensorial deprivation or exposure to noise or other forms of ambiguous stimulation.\(^7,\,8,\,9\) In this case, the patient developed auditory and visual hallucinations after having hearing and visual losses.

Severe psychiatric symptoms of depression, psychosis and organic brain syndrome are reported in up to 25% of patients.\(^10\) Despite family studies indicate autosomal recessive inheritance, there is no convincing evidence of an increased risk of psychiatric illness in the first degree relatives who may be carriers.\(^11\)

With regards to medical presentations, diabetes mellitus was the presenting symptom in 78% of cases.\(^12\) The presenting age ranges from 3 weeks to 16 years with median age of 6 years.\(^4\) It is non-autoimmune, insulin deficient, and non-HLA linked. Microvascular complications are rare and seem to develop slower than in type 1 diabetes.\(^4\) Partial cranial diabetes insipidus occurs in about three quarters of patients at a median age of 14 years (ranges from 3 months to 40 years) and respond to vasopressin treatment.\(^4\) The magnetic resonance imaging showed loss of signal on hypothalamus and posterior pituitary clearly proved the cranial nature of insipidus.\(^4\)

The presence of optic atrophy in a patient with type 1 diabetes of short duration has alerted the clinician to the possibility of Wolfram syndrome.\(^13\) The optic atrophy is progressive and eventually leads to blindness irrespective of the level of diabetic control.\(^14\) The presenting age ranges from 6 weeks to 19 years with median age of 11 years.\(^4\)

A neurosensory deafness in this patient had been ascertained by the audiometric assessment. The audiometric abnormalities
have been reported in 60 percent of patients with high tone nerve deafness as the characteristic feature.\textsuperscript{14} Symptomatic sensori-neural deafness develops in two thirds of patients at a median age of 16 years (ranges: 5-39 years); and a quarter of these requires hearing aids for high frequency loss. Dilated renal outflow tracts presents in two thirds of patients at median age of 20 years (ranges from 10-44 years); with urinary frequency, incontinence and recurrent infections.\textsuperscript{4,15}

References


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CASE REPORT

Bilateral Blurred Disc Margins in a Case of Schizophrenia

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Abstract

Papilledema is always of importance to the psychiatrist as sometimes underlying pathologies like mass lesions or conditions which raise the intracranial tension may present with psychiatric symptoms. We report a case of schizophrenia in whom there was an incidental finding of asymptomatic bilateral blurred disc margins as the patient was being investigated for ECT workup. The underlying psychiatric symptoms improved but the cause for the bilateral blurred disc margins could not be ascertained despite all the investigations.

Keywords: Papilledema, Blurred Disc Margins, Schizophrenia

Introduction

Papilledema which is one of the signs of raised intracranial tension can be identified as optic disc swelling and blurred disc margin on fundoscopy. Various organic causes such as mass lesions, optic neuropathy and tumours, vasculopathies, intraocular diseases, venous obstruction, conditions causing increased CSF protein levels and pseudopapilledema can present with papilledema1. Optic disc drusen is another pathology where there may be the appearance of an elevated optic disk resembling papilledema. Although many patients are asymptomatic, there are reports of visual field and acuity loss2.

Papilledema is always of importance to the psychiatrist as sometimes underlying pathologies like mass lesions, different optic neuropathy and tumours, macular degeneration, cataract, intraocular diseases, may present with psychiatric symptoms and the predominant psychopathology seen are depression, mania, psychosis, anxiety, apathy, cognitive or personality changes3-6. It is often during fundoscopy that the cause gets detected especially, if the patient does not show any other signs of organic pathology. We too found clinically asymptomatic bilateral blurred disc margins in a case of schizophrenia, where the cause for the blurred disc margins could not be detected.

Case

A 23 year old unmarried male was referred to a tertiary care centre from a rural town in view of no improvement in his psychiatric symptoms. The patient was diagnosed as a case of disorganised schizophrenia and was on treatment from a psychiatrist for the last
4 years. His symptoms included muttering and gesticulating to self with inappropriate smiling, wandering away from home, collecting paper, garbage and poor self care. Though he would exhibit aggression towards family members and abuse people, there were no delusions and hallucinations elicited. He would be irrelevant and had loosening of associations. His sleep and appetite were disturbed. The patient was tried on several typical and atypical antipsychotic medications in adequate dosage for an adequate period over the last 4 years, with 2-3 months of non-compliance every year, after which the medication would be restarted. Currently since 4 months, he was on oral trifluoperazine 20 mg, olanzapine 10 mg, risperidone 2 mg, clozapine 50 mg, amisulpride 150 mg and quetiapine 100 mg. Despite being on so many drugs, the patient was still very abusive, aggressive, dishevelled, irrelevant and had not taken bath for many days. He had wandered away for a few days and when he was found his father got him to our hospital. Due to the chronicity and the continuous nature of the symptoms, we decided to admit him and consider electroconvulsive therapy. He was given oral risperidone 4 mg and trihexyphenidyl 4 mg in divided doses while all his other medications were already discontinued when the patient had wandered away.

The patient was routinely investigated and all his blood parameters were normal. However on fundoscopy, the ophthalmologist reported bilateral blurring of optic disc margins, obliterated cups, hyperaemic disc and elevation of the optic disc in both eyes. In view of the above findings, the ophthalmologist wanted to investigate the cause for bilateral papilledema in the patient. A neurology reference to rule out the various causes for papilledema did not reveal any pathology or organic antecedents for the same.

The detailed ophthalmologic assessment revealed visual acuity 6/6 in both eyes. Intraocular pressure was 20 mm of Hg in both eyes. Direct and indirect reflexes were intact with no relative afferent papillary defect. Extraocular movements were full. Visual field examination and perimetry were normal. Anterior segment examination was normal without iris pathology or cellular reaction. MRI brain and orbits revealed no evidence of an acute infarct or pituitary, suprasellar or intracranial mass. The ultrasonography B scan of both eyes did not reveal any posterior segment pathology or optic nerve drusen and was completely normal. The fundus fluorescence angiography was done to see retinal vessels which were also normal. Ultimately the patient who was clinically asymptomatic for the causes of papilledema was considered as having bilateral blurred disc margins by the ophthalmologist.

Meanwhile the patient’s psychiatric symptoms improved over the 4 weeks he was admitted and he did not require ECTs for which the investigations were initially carried out. The father was educated about the illness and prognosis and was also explained about expressed emotions. The patient was also seen by the social worker and the occupational therapist and was given social skills training. He was advised to help his father in farming and herd the cattle and to follow up regularly once in 3 months as he was staying about 500 km from our hospital.

**Discussion**

This patient of ours was investigated for the various causes of papilledema and was eventually diagnosed as having bilateral
blurred disc margins as no cause could be elicited. The differential diagnosis of papilledema (with normal visual acuity and bilaterality) includes anomalous elevation of the optic discs which occurs in about 1% of the population, probably caused most often by buried optic disc drusen or hypoplastic discs which may be anomalously elevated or tilted optic discs which often show elevation of their superior and nasal portions\(^7\). There are some case reports where patients were having unilateral papilledema which was asymptomatic\(^8\) but the aetiology for the same remained obscure as in our case. In psychiatric patients it is important to ascertain whether the psychopathology is due to an underlying organic cause or is purely functional. Also psychiatric patients having schizophrenia may not be able to tell symptoms of blurring of vision or raised intracranial tension in the midst of their florid psychotic symptoms and the organic aetiology could therefore be missed. Many psychiatric medications also cause blurring of vision due to anti-cholinergic side effects and hence the psychiatrist may not also pay heed to that symptom.

Our patient had been diagnosed as a schizophrenic and was on treatment. However details of whether he suffered any organic insult, head injury, seizure, history of being beaten etc was not available from his father as patient had periods of wandering away from home and could not give the details about where he had been wandering or if he suffered from any injury. The chronic and continuous nature of symptoms with a history of poor response to medication made us consider ECT as a treatment option.

The incidental finding of the bilateral blurred disc margins also made us review the diagnosis for organic antecedents as well as investigate the patient thoroughly to determine the cause for the same. However the aetiology or its relation to schizophrenia could not be ascertained. Fortunately the psychiatric morbidity improved and the patient was discharged but has been asked to keep a regular follow up in psychiatry for the maintenance treatment of schizophrenia as well as in ophthalmology to ascertain early interventions if the patient become symptomatic for papilledema.

Acknowledgement

We would like to acknowledge Dr S R Parkar, Professor and Head ,Psychiatry for her support.

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CASE REPORT

Clozapine-induced Constipation: A Case Report

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2Department of Psychiatry and Mental Health, Hospital Pulau Pinang, 10990 Pulau Pinang, Malaysia

Abstract

Clozapine is an atypical antipsychotic medication, used primarily as the drug of choice in treatment resistant schizophrenia. Despite its considerable advantages, clozapine’s licence is restricted because of its potential to induce agranulocytosis. Hence, white blood cell count monitoring is mandatory in patients receiving clozapine treatment. A side effect of clozapine that has received relatively less attention is constipation, which is caused by the drug’s anticholinergic effect. This potentially serious problem can result in life-threatening bowel obstruction, ischemia, necrosis, perforation, and pulmonary aspiration. Despite this evidence, routine inquiry about constipation in clozapine treated patients is not emphasised in current clinical guidance. We report a case to highlight constipation as both a potentially serious side effect and as a factor, insufficiently recognised, in non-adherence to clozapine.

Keywords: Clozapine, Side Effects, Constipation, Non-adherence

Introduction

Clozapine is a tricyclic dibenzodiazepine derivative classified as an atypical antipsychotic. It is recommended in treatment resistant schizophrenia, defined as a lack of response to at least two antipsychotics after a trial of 6–8 weeks.1 Other advantages of the drug include a relatively low risk of extra pyramidal symptoms and an association with significantly reduced suicidal behaviour in patients with schizophrenia.2 Despite these added benefits in comparison to other antipsychotics, clozapine’s prescribing licence is restricted because of its potential to induce agranulocytosis. Before clozapine is prescribed, patients must be either refractory to or have experienced intolerable side-effects from at least two different antipsychotics. In addition, white blood cell count monitoring is mandatory in patients receiving clozapine treatment.3

Other than agranulocytosis, important potential side effects of clozapine include seizure, myocarditis, diabetes, weight gain and metabolic syndrome.4 A side effect that has received relatively less attention, however, is constipation, which is caused by the anticholinergic effect of clozapine. This potentially serious problem can result in life-
threatening bowel obstruction, ischemia, necrosis, perforation, and pulmonary aspiration.\textsuperscript{5,6} Despite this evidence, routine inquiry about constipation in clozapine treated patients is not emphasised in current clinical guidance.\textsuperscript{3}

Here, we report the case of a patient receiving clozapine for treatment resistant schizophrenia who was persistently non-adherent due to constipation as a side-effect of the drug. We describe the consequent impacts on the course and outcome of the patient’s illness. We discuss the case in light of previous literature on the association between constipation and clozapine and address recommendations for changes in current guidance for clinicians prescribing this medication.

**Case Report**

A 24-year-old female was prescribed clozapine for treatment resistant schizophrenia, after separate trials of three antipsychotics and following a serious suicide attempt at the age of 18.

Premorbidly, the patient reported an unhappy childhood and interpersonal difficulties at school. She had been a quiet person and was socially isolated from peers. Complaints of being talked badly about by peers had apparently led to several transfers of school during her secondary school years. The patient had four inpatient psychiatric admissions in all since being diagnosed at 16 years old.

After commencing clozapine, the daily dose had been gradually titrated up to 250 mg. However the patient was not adherent and reduced the dosage to only 50 mg daily due to the side effect of constipation which she found distressing and unacceptable. She appeared not to have revealed this to the treatment team before experiencing a further relapse resulting in her third hospital admission. During this admission, and after she had revealed the reasons for her non-adherence, the patient was persuaded to take clozapine 50 mg BD which was supplemented with the depot anti-psychotic, flupenthixol 40 mg monthly by intramuscular injection. She had been maintained on this medication regime up to her fourth in-patient psychiatric admission. Besides that, laxatives were also prescribed during follow-ups in the clinic. However, the patient was not committed in taking the laxatives prescribed as she was afraid of the side effects that the medications might cause. During the fourth admission, the patient had residual paranoid delusions besides showing poor insight to her mental illness. However, she had experienced no auditory hallucinations since her previous admission.

In response to further questioning by the first author (TYW), the patient acknowledged that she had again failed to take her oral medication as prescribed in the period prior to her readmission. She revealed that this was because of the persistent problem of constipation. In an effort to minimise the constipation, she admitted that she had omitted the morning dose of clozapine and only took the night-time dose.

Following this revelation, laxatives were subsequently prescribed again by the treating psychiatrist, and the patient was counselled well on her illness and the importance of taking medications as prescribed to prevent further relapse.

During the subsequent follow-up in the clinic few months later, the treating team decided to withdraw the monthly depot injection and establish the patient on clozapine monotherapy in view of her
improved adherence to clozapine which she was now taking at the prescribed dose of 125 mg daily. The current treatment plan is for a gradual increase in the dose of clozapine in order to achieve the drug’s optimal therapeutic effect on residual symptoms and functioning.

Discussion

We have described the case of a 24-year-old female with treatment resistant schizophrenia, and significant suicidal risk, who was persistently non-adherent to clozapine due to the side effect of constipation.

The patient’s history suggests that even the low dose of clozapine the patient found acceptable, was of some benefit in reducing the frequency of auditory hallucinations. It seems likely, therefore, that her residual paranoid delusions, which were clearly disabling, might have also responded if she had taken clozapine at the prescribed dose. The remediable side effect of constipation, therefore, through its negative impact on adherence, appears to have significantly undermined the potential benefits of the drug in terms of symptoms, functioning and lessening of the future risk of suicide.

The evidence arising from our case supports the previous literature suggesting that constipation associated with clozapine is insufficiently recognized and that screening guidelines should be modified to include routine screening questions regarding constipation in patients considered for or maintained on clozapine therapy.7

In addition, our case prompts consideration of the question of why clozapine associated constipation may be not be adequately recognised? In this, we suggest that both clinician and patient factors may contribute. From the physician perspective, because of the restriction in the licensing of clozapine, it may be that clinicians are preoccupied with the need for close monitoring of clozapine’s more widely known haematological risks. It may be, also, that many are simply unaware that the frequency of constipation in clozapine treated patients is actually much higher than the frequency of agranulocytosis and the mortality is also higher at 15 %-27.5 %, compared to the mortality rate of 0.1 %-0.3 % for agranulocytosis.7

From the patient perspective a possible factor may be that some patients may not easily report the problem of constipation and be more inclined to attempt to deal with it themselves and without discussion with their prescribing doctor. This, in turn may be related to the personal nature of the side-effect and possible embarrassment associated with raising it with the prescribing physician. Further research could usefully explore these and other possible contributors.

Conclusions

This case highlights how important it is for clinicians to recognise and actively treat clozapine related constipation in order to lessen the risk of non-adherence, and increase the likelihood of exposure to the medication at a therapeutic dose. Hence, it is recommended that constipation be added to the screening guidelines of patients on clozapine therapy in this country. We recommend routine, sensitive questioning regarding (a) whether a patient considered for clozapine treatment has a previous history of chronic constipation and/or (b) is experiencing constipation since commencement of the drug.
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Suicide and Gambling on the Public Record

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Abstract

Objective: Current western medical wisdom is that suicide is always or almost always the result of mental disorder. Our objective was to explore the public record for a relationship between suicide and gambling, in the absence of mental disorder. Method: The public record was examined for examples of individuals without stated evidence of mental disorder who completed suicide in the setting of recent gambling losses. Results: We identified a 17th century opinion suggesting gambling losses could lead to suicide, and 10 individual cases (including a decorated policeman, a professional athlete and two engineers). Conclusions: This evidence strongly suggests that in the absence of evidence of mental disorder, gambling losses may lead to suicide.

Keywords: Gambling, Suicide, Mental Health

Introduction

Suicide is more common among people with mental disorder than those without mental disorder. The lifetime risk of suicide among people with major depressive disorder is 4-5%, which is much higher than the lifetime risk in the general population. Psychological autopsies in the west have consistently found that all or nearly all of those who complete suicide have suffered mental disorders.

However, recent psychological autopsies in the east have found mental disorder in less than 50% of those who completed suicide. This raises important questions about the methodology of earlier psychological autopsies, and suggests other factors may be important.

Our group suggested the concept of “predicament suicide” in which suicide is considered as a response to intolerable circumstances/predicaments. These predicaments are of two main types, 1) intractable or untreated mental disorder, and 2) social or environmental stressors. Naturally, individual cases may feature both types simultaneously.

With a view to further understand the social/environmental drivers of suicide (which may coexist or separately exist from mental disorder), we have examined accounts of suicide on the public record (from mythology, history, and lay press). We have provided evidence that suicide of apparently mentally healthy individuals may be associated with loss of reputation, recent
legal problems arising from pedophilic activity\textsuperscript{9}, moral dilemma\textsuperscript{10}, and the loss of life savings\textsuperscript{11}. We have also reported suicide pacts, in which the loss of health of one or both members was a powerful driver\textsuperscript{12}. We are currently gathering evidence of forced marriage resulting in suicide.

We are interested in cases where there is no stated evidence of mental disorder. In this paper we explore the public record for evidence that gambling losses may be associated with suicide. However, as pathological gambling appears in the DSM IV, and it is probable that many individuals described here would satisfy that diagnosis, we are particularly interested in individuals who do not appear to have a mental disorder “other than pathological gambling”.

We contend that all those who suicide are suffering low spirits, dejected, disappointed or demoralized. However, low spirits unless accompanied by other symptoms, do not satisfy the diagnostic criteria of any mental disorder. Strong warnings have been given not to medicalize low spirits\textsuperscript{13,14}.

We are not concerned here with the debate of whether pathological gambling is an addiction, obsession or problem\textsuperscript{15,16}. Instead, we are interested to know whether there is evidence that gambling losses are associated with suicide.

Statements are frequently made by groups opposed to gambling, claiming potential damaging social effects. In a case series of 44 completed gambling-related suicides\textsuperscript{17} putative risk factors were comorbid depression, relationship difficulties, and large financial debts. A recent national survey of psychiatric morbidity of adults in England\textsuperscript{18} reported that those in debt were twice as likely to think about suicide after controlling for sociodemographic, economic, social and related factors.

**Methods**

We examined a range of public records, from mythology to historical texts and news reports (including those available on the internet) for examples of suicide in the setting of gambling. While a broad net was cast, we paid particular attention to the last 70 years, as during this time diagnostic criteria of mental disorders achieved some degree of standardization.

**Results**

*“The Anatomy of Melancholy”*

This review focuses on individual cases. However, some relevant comments were made by Robert Burton in early 17\textsuperscript{th} Century book “The Anatomy of Melancholy”\textsuperscript{19}. He wrote (page 287) that when ‘Love or Gambling’ leads to a loss of all funds, the individual is “left to Shame, Reproach, Despair”. He further stated (page 264) that “a modest man” would “lose his life” rather “than suffer the least defamation of honor”. Thus, at least one author of 400 years ago supported the notion that gambling losses could lead to suicide.

**Marc-Antoine Calas** (28 years, died 1761)

Marc-Antoine was a son of a Protestant family living in Toulouse, France. He ate a meal with his family and then suddenly disappeared, but was found dead, hanged. The locals assumed that he was preparing to embrace the Catholic faith (as had his younger brother, Louis, a year earlier) and that his father (Jean) had murdered him to prevent this event. Some months later Jean was convicted, broken on the wheel, strangled and his body burnt to ashes\textsuperscript{20}. Family property was confiscated and other members of the family were mistreated.
There had been injustice and eventually Calas’s conviction was reversed and the family paid an indemnity. Voltaire\textsuperscript{21} was a leading protester and stated that Marc-Antoine “having lost all his money in gambling, he chose a most proper opportunity for executing his design”. The details of this case are sketchy, nevertheless, the indications are that during the 18\textsuperscript{th} Century, gambling losses could lead to suicide.

**Stuart and Gertrude Ross** (47 and 46 years, died 1936)
Stuart, a ship’s engineer and his wife, Gertrude, lived in Sydney, Australia. They placed a note on the door, “Please turn gas off”. They attached a rubber tube to their gas stove and lay on the kitchen floor with the other end of the tube and covered themselves with blankets. They died by asphyxiation. The coroner found that gambling debts were the reason for their suicides\textsuperscript{22}.

**Carol Warriner** (63 years, died 1996)
Carol lived with her husband Skip near Joliet, Illinois\textsuperscript{23}. She was a retired successful real estate agent. Skip had worked in a chemical factory but was disabled by heart and circulation problems. Carol gambled on the casino boats that operated out of Joliet. She lost their house and savings and was US $200 000 in debt. She wrote a note saying, “There is no one to blame but me and the monster inside”. She also wrote, “Any help you can give with Skip would be appreciated”. She attached a hose to the exhaust of their car and died by asphyxiation.

A week later, Skip died by the same means (in the same car).

**Solomon Bell** (38 years, died 2000)
Solomon was a decorated sergeant who had been in the Detroit Police Department for 12 years. He lived alone in a large house in a well-to-do suburb; he was a sociable man and owned a number of cars including a Cadillac and Jaguar. On his last day he lost money gambling at the MotorCity casino, and then moved on to the MGM Grand Detroit casino, but his luck did not change. At the high-stakes blackjack table he repeatedly doubled his bets and repeatedly lost. He stood up from the table took out his service revolver and shot himself in the head\textsuperscript{24}.

His friends and co-workers knew him to be a recreational gambler. One said, “There were no indications that he was experiencing any difficulty in any aspect of his personal or professional life”.

**Mario Opalka** (44 years, died 2002)
Mario was a council planning officer in Lancashire, UK. He cared for his wife who died of cancer in 2000. He became deeply involved in internet casino gambling, and hanged himself when his debts were in the order of UK Pounds 53 000\textsuperscript{25}.

**Katherine Natt** (24 years, died 2006)
Katherine lived in Adelaide, South Australia\textsuperscript{26}. She had two children and was co-habiting with a man who was not the father of either child. She was a card dealer at the Skycity Adelaide Casino. Katherine was a heavy user of poker machines in hotels (staff of the Skycity Casino are not allowed to bet at that facility). She was deeply in debt, and although her father had taken over some of her debt and was paying her utility and other expenses, she continued to gamble.
She took a large overdose of paracetamol, wrote a suicide note, and died in hospital of liver failure. In her suicide note she wrote, ‘I ruined my marriage with my pokie addiction and then it affected my Dad financially’. She continued that she feared her debts may cause her to lose custody of one or both of her children.

While stressors included Katherine’s father being financially damaged, and that she could lose the custody of her children, both of these traced directly back to her gambling debts.

**Brian Rockall** (43 years, died 2009)
Brian lived with his mother (Valerie, 81 years) in a flat in a well-to-do suburb of Edinburgh, Scotland. He had no history of convictions and described himself in court when he was a witness on an unrelated matter some years earlier as, ‘a professional gambler’. He was an online gambler with UK pounds 10 000 in debt and had not paid utilities or rent for months.

Valerie was found stabbed to death and Brian was found hanged. It is speculated that when Valerie discovered the extent of her son’s debt, he murdered her and hanged himself. Police said, “Until the tragic events this week, he has not been on anyone’s radar for any reason. He, to all intents and purposes, was just a man living with his elderly mother and leading an unremarkable life”.

**Kenny McKinley** (23 years, died 2010)
Kenny was a talented, highly-paid professional athlete based in Denver, USA. He had twice injured a knee, which placed his career in some doubt. He was paying child support for a son. He was a frequent gambler and was deeply in debt. His parents and a small number of friends tried to help him with his debts. He owed US$ 40 000 in gambling debts and US$ 65 000 to one of his friends (covering one of his debts). He shot himself in the head.

**Ti Pwar and Kay Win** (39 and 37 years, died 2011)
Ti Pwar operated a gold shop in the Gyobingauk Market (Burma) where he lived with his wife, Kay Win, and three year old daughter, Pon Sone. Ti Pwar and Kay Win also sold lottery tickets. They gambled heavily on soccer matches. They had accrued gambling debts of (US$ 337,078). They wrote a suicide note stating that they did not want Pon Sone to be disgraced, and murdered her, before completing suicide with insecticide. When the bodies were found a Buddhist sermon was playing on a CD.

Locals told reporters that gambling was rife and five other people (including a teacher) had died because of debts by drinking insecticide in the last year.

**Sandy Muirhead** (63 years, 2012)
Sandy was an engineer, married to Gill and the father of twin daughters. They lived in Birmingham, England. He secretly gambled on slot machines. He could cover his losses until he lost his job, and could only find casual contracts. He had a large overdraft and a loan and had milked their assets. When he could no longer borrow money he hung himself.

Gill describes Sandy as likable and relaxed, “Any more laid back and he would have been horizontal”. She continued, “He was a good husband and father, much loved by family and friends and respected by those he worked with”.

**Results Summary**

We have located an opinion in the early 17th
Century “The Anatomy of Melancholia” suggesting that gambling debts can lead to suicide.

We have located 10 individual cases on the public over the period 1761 to 2012. Due to suicide pacts there were 12 individuals involved, 8 male, 4 female; the age range was 23 to 63 years. In no case was there mention of mental disorder. In at least two of these there were clearly other stressors, in one case a man had nursed his wife till she died two years earlier, and in the other a highly paid athlete who had injured his knee. There were two suicide pacts, and two murder-suicides.

While this is a heterogeneous group, these cases strongly suggest that gambling losses may be associated with suicide.

Discussion

Current medical wisdom states that all or almost all those who complete suicide do so in response to mental disorder. In this paper we have provided evidence strongly suggesting that gambling debts may be a trigger for suicide. This is consistent with our earlier observation of social/environmental factors playing a role in some suicides. While a small series of cases taken from the public record does not prove a connection, it does provide important qualitative information.

Using the public record, as we have, leaves open the challenge that lay reporters may not have noticed important clinical indicators of mental disorder. In response, reporters routinely seek out evidence of mental disorder and are quick to point out failings of the health systems. Their work is open to scrutiny and their continuing employment depends on accuracy. While they may lack the knowledge of clinicians, this may be balanced by the lack of bias which clinician may harbor. This paper is not quantitative, but merely seeks to demonstrate that gambling losses are among the social/environmental factors which may lead to suicide.

A psychological autopsy of pathological gamblers who had completed suicide found 82.4% suffered associated mental disorders (mainly depressive disorders and substance use disorders). This needs to be accepted with caution as psychological autopsies can feature methodological difficulties. While depressive disorders and substance use disorders may have been present, this does not mean the economic losses from gambling did not play a significant role. Further, this autopsy nevertheless found no mental disorder in 17.6% of gamblers who took their own lives, leaving gambling stress as the only factor. It seems clear, however, is that gamblers with large debts are unlikely to seek help for psychiatric disorders.

As mentioned, two of the ten cases detailed had additional social/environmental stressors – one individual had been bereaved two years earlier, and one individual’s income was under some threat because of a knee injury.

It came as a surprise that two cases were associated with murder-suicide. It is probable that in one case parents decided to kill their daughter to spare her from disgrace. It is possible that in another case a man unpremeditatedly killed his mother when she confronted him with his debts.

Until recently, the importance of mental disorder in suicide was emphasized. However, it has recently been confirmed that suicide can occur in the absence of mental disorder. A paper on “Suicide and...
Impossible Worlds finds that the worlds of suicidal people are “impossible/unlivable; gambling losses may place people in “impossible worlds”.

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Epigenetics, Mental Health and Transgenerational Epigenetic Effects

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Abstract

Objective: to review the field of epigenetics, and present basic and recent material that may be of interest to clinical psychiatrists. We include basic molecular mechanism, a consideration of findings related to mental disorders, evidence of sustained effects, and the evidence for and implications of transgenerational epigenetic modifications. Method: we examined all the available papers for the last five years identified by PubMed using the words ‘epigenetics’ and ‘epigenetics psychiatry’, and the available leading specialized textbooks. Results: we report on molecular mechanisms including DNA and histone modifications, and non-coding RNAs. While some modifications are short-lived, others are life-long. Depression, suicide, schizophrenia, PTSD, borderline personality disorder and drug addiction are among the conditions for which epigenetic involvement has been proposed. Transgenerational epigenetics enables the environmental experience of one generation to be non-genetically inherited by subsequent generations. This has been molecularly demonstrated in laboratory animals and epidemically suggested in humans. Conclusions: epigenetics provides a new way of understanding human behavior and points to potential therapies for mental disorders. Should it transpire that transgenerational epigenetic modifications apply with force in humans as they do to laboratory animals, this will emphasize the need for cultural shift, safe societies with ample opportunities.

Keywords: Mental Disorders, Psychiatry, Epigenetics, Health, Histone, DNA Acetylation

Introduction

For decades we believed that nature (genetic endowment) and nurture (environment) determined our phenotype (physical and behavioral assets and diseases) and there were no other significant influences. Recently we have learned of a new level of influence, the epigenome, which provides a molecular explanation of the nature-nurture interaction, and allows a mechanism for altering the phenotype, not only in the young, but throughout life1.

Epigenetics is an emerging field which will impact on our understanding of mental
health. While the definition has been debated at an esoteric level\textsuperscript{2,3}, the following is adequate for our purposes: “The study of mitotically and/or meiotically heritable changes in gene formation that cannot be explained by changes in DNA sequence”\textsuperscript{4}. Thus epigenetic modification may explain how environmental features effect life-long changes in phenotype of the individual and even transgenerational gene expression in offspring.

Adverse conditions during early life are a risk factor for stress related diseases such as depression and post-traumatic stress disorder\textsuperscript{5}. Such studies suggests epigenetic factors may have a role to play is these and other mental disorders.

Molecular Mechanisms

Chromatin
Chromatin is the combination of DNA and proteins which are contained in the nucleus. The DNA is coiled around histone proteins. The basic unit of chromatin is the nucleosome, which is composed of about 147 base pairs of DNA wrapped around (about 1.65 turns) a core histones (two copies of four different histones)\textsuperscript{6}. Each histone has an amino-terminal ‘tail’ composed of amino acid residues.

In simple terms, chromatin exists in two basic states. In ‘condensed’ chromatin (heterochromatin), the DNA and histone cores are tightly packed, transcription is not possible and the gene is inactive or ‘silenced’. In ‘relaxed’ chromatin (euchromatin) transcription is possible and the gene is termed ‘active’.

DNA modification
One epigenetic adaptation which regulates (usually suppressing) gene expression is the addition of methyl groups to DNA. These come from S-adenosyl methionine (SAM) and are transferred to cytosine residues where the cytosine nucleotide occurs next to a guanine nucleotide (CpG). The cytosine is thereby converted from cytosine to 5-methylcytocine. This process is catalyzed by DNA methyltransferases (DNMTs)\textsuperscript{7}.

High concentrations of CpG sequences occur in ‘promoter regions’ - segments of DNA where DNA transcription complexes bind when they begin copying the DNA to make RNA.

Histone modification
Each histone has an amino (N) terminal tail. Acetylation of tails causes the relaxation chromatin, and allows active gene transcription. The catalyst is histone acetyltransferases (HATs), and is reversed by histone deacetylases (HDACs)\textsuperscript{8}. In contrast to acetylation, histone methylation can cause either with gene activation or repression, depending on the residue being methylated. For example, methylation of histone H3 at Lys9 is associated with gene silencing\textsuperscript{9}.

Modifications can also be accomplished by a range of other processes, including phosphorylation, ubiquitylation and SUMOylation\textsuperscript{7}.

Non-coding RNAs
Non-coding (nc)RNAs are a new source of influence over gene regulation\textsuperscript{10}. A classification includes ‘small’, 20-200 nucleotides (nt) and ‘long’ ncRNAs, greater than 200 nt. For a detailed review see Spadaro and Bredy\textsuperscript{11}. Small ncRNAs include micro (mi), short interfering (si), and P-element induced wimpy testis (PIWI)-interacting (Pi)RNAs\textsuperscript{12}. MicroRNAs are endogenous and mediate gene silencing by binding to their target mRNA. Around 200 miRNAs have been identified to the present
time, and more than 33% of the mammalian genome is subject to miRNA regulation.

**Further mechanism**

Epigenetics is an emerging field; further mechanisms will be identified. The influence of the immune system on epigenetic processes will provide valuable information.

**Long-Term Phenotype**

Epigenetics provides and explanation for the mystery of how cells of multicellular organisms (including humans) are genetically homogeneous but may be structurally and functionally different (liver and brain cells, for example).

Human cardiovascular disease has origins in early life but may not become apparent till later in life, and the likely mediator is epigenetic dysregulation of gene expression.

While epigenetic changes may only persist for short periods, others, as in the differentiation mentioned in the first paragraphs, may persist across the lifespan. Many animal studies demonstrate the lasting effects of early life experiences. Good rat mothering of pups includes high level of licking, grooming and arched back nursing (high LG-ABN); naturally, some mothers demonstrate low LG-ABN. When the pups of low LG-ABN mother are switched to a high LG-ABN, and subsequently have their own litters, their offspring demonstrate high LG-ABN. The offspring of high LG-ABN mothers, compared to offspring of Low LG-ABN mothers, are less anxious, have attenuated corticosterone responses to stress and increased expression of glucocorticoid receptor mRNA and protein in the hippocampus.

It is not only the newborn that are subject to environmental influence. Mammalian studies have demonstrated experience dependent epigenetic modifications in adults which may have long-lasting effects within mature neurons.

As is widely accepted, children who are neglected or maltreated are at risk of developing lasting emotional and behavioral problems. The major mechanism is DNA methylation, which predisposes these individuals to stress-related problems in later life.

**Specific Mental Health Disorders**

**Mood Disorders**

Chronic social defeat stress in mice (a model of depression) is associated with chromatin remodeling by increased histone methylation at the promoter regions of BDNF genes in the hippocampus. Imipramine treatment reversed this process by histone acetylation at the promoters. Thus, in the sub-primate mammals, histone remodeling appears to have been implicated in the pathophysiology and treatment of depression.

This is consistent with human studies which have demonstrated low levels of BDNF in depressed compared to healthy individuals, which in turn are raised by antidepressant treatment. The treatment of depression with citalopram decreases histone methylation levels at the BDNF gene. Subsequent increases BDNF levels are related to the antidepressant response.

At the clinical level, features of depression including the gradual onset and slow response to treatment, suggest slowly developing but stable adaptations, which is consistent with epigenetic regulation.
In bipolar disorder, a study of monozygotic twins discordant for the disorder, demonstrated a role for DNA methylation differences in mediating the phenotypic difference\(^27\). A GABAergic system dysfunction has been proposed in bipolar disorder. This is supported by the finding of GABAergic gene expression downregulation which was demonstrated in postmortem brains of people who had suffered bipolar disorder\(^28\).

**Suicide**

Suicide is not always the result of mental disorder\(^29\), however, this does not exclude biological explanations, and such explanations can be reasonably expected to be similar to the findings in mood disorders.

One study examined the epigenetic differences in a glucocorticoid receptor (NR3C1) promoter in the postmortem hippocampus of people who completed suicide\(^30\); those with a history of childhood abuse were compared with those without. Changes suggested an effect of parental care on the epigenetic regulation of hippocampal glucocorticoid receptor (GR) expression; those who had been abused children displayed low GR levels and elevated DNA methylation of the GR promoter.

Low levels of BDNF have been reported in suicide. A postmortem study of the Wernicke area of suicide subjects found hypermethylation of the BDNF promoter, which could explain the downregulation of BDNF expressed in this population\(^31\).

In a recent genome-wide investigation of the brains of suicide subjects, broad reprogramming of promoter DNA methylation patterns in the hippocampus were demonstrated\(^32\). At this stage, the definitive modifications related to suicide have not been identified.

**Schizophrenia**

Both genetic and environmental factors are involved in the etiology of schizophrenia (33). While the liability to schizophrenia is strongly heritable\(^34\), however, about 90% of those who develop this disorder do not have a parent with this disorder. Therefore, environmental factors are important in the etiology of this disorder\(^35\).

Some work has highlighted epigenetic alterations at the reelin promoter. Reelin is a glycoprotein found in adult GABA containing neurons. Postmortem studies of people who suffered schizophrenia have demonstrated down-regulation of reelin expression is several parts of the brain\(^36\). This could cause dysfunction of GABA-system\(^7\).

Also consistent with the GABAergic pathology theory of psychosis, evidence for aberrant epigenetic regulation of GABAergic signaling was found in postmortem prefrontal cortex of people with a history of schizophrenia. Clozapine, olanzapine and quetiapine were shown to facilitate chromatin remodeling, while haloperidol and risperidone are inactive in this respect\(^28\).

A genome-wide study of peripheral blood of monozygotic twins discordant for schizophrenia has reported differences in DNA methylation, which may help to explain the different phenotypes\(^27\).

**Unwanted fear and PTSD**

Long-term memory formation is achieved via selective changes in gene expression. Unwanted fear and post-traumatic stress disorder (PTSD) appear to be underpinned by epigenetic changes secondary to the obvious stressor. In the rat, fear learning is associated with altered DNA methylation
and histone modification at the BDNF gene locus in the hippocampus of adults. Rodent models of PTSD are used in early therapeutic investigations. In one rat study, garcinol, a naturally occurring histone acetyltransferase (HAT) has been shown to disrupt the consolidation and reconsolidation of Pavlovian fear conditioning. Garcinol was administered both systemically and by injection into the lateral amygdala. Both disrupted consolidation and reconsolidation of unwanted memories, which was associated with acetylation of histone H3 in the lateral amygdala. The authors suggest that the use of a HAT inhibitor in combination with psychotherapy may have therapeutic potential.

**Borderline personality disorder**
One of the established etiological factors of borderline personality disorder (BPT) is adverse childhood experiences. Down-regulation of BDNF gene expression associated with methylation at promoter sites has been described in BPD. In a study of people with BPD the percentage of methylation at two BDNF gene CpG sites was determined. BPD people had significantly higher methylation at both sites, compared to controls, and the severity of abuse was proportional to the degree of methylation. Psychotherapy was then provided, and those who had a clinical response showed a decreased methylation status. These results support the theory that BPD is associated epigenetic interference with the BDNF gene and that this abnormality may be corrected by appropriate treatment.

**Alzheimer’s disease**
The possibility that epigenetic mechanisms play a role in etiology of Alzheimer’s disease has supported. In mouse memory impairment (model of Alzheimer’s disease) enhancing histone acetylation using HDACs can ‘rescue’ memory deficits. This approach may have utility in the treatment of Alzheimer’s disease.

**Drug and alcohol addiction**
Drugs of abuse exert control over addicted users by commandeering the brain reward centers. Changes have been demonstrated in the mRNA levels in the ventral tegmental area, nucleus accumbens, hippocampus and other brain centers which may be long-lasting. Chronic alcohol use leads to histone modifications and DNA methylation in the amygdala. Stimulant addiction is associated with histone modification, DNA methylation and miRNAs may all contribute to altered BDNF expression.

While epigenetic modifications have been identified in drug addiction, discussion continues as to whether/which of these are predisposing factors and which are responses to drug use.

**Other psychiatric disorders**
It is probable that epigenetic modifications will be important in other psychiatric disorders. Eating disorders and stress responsiveness and anxiety have received recent some attention.

**Transgenerational Epigentic Modification**
The possibility that the phenotype of offspring being influenced by the environmental experience of his/her parents is of profound importance in mental health. It may mean that adverse early life experience and the war (or similar) experience of adults could have damaging effects on subsequent generations, further emphasizing the responsibility of society to provide for the disadvantaged and prevent war and other trauma.
Epidemiological studies demonstrate that environmental factors can, in the absence of DNA sequence changes, result in particular phenotypes in subsequent generations. When food is not readily available during the period prior to the growth spurt of men, cardiovascular disease mortality is reduced in the next generation. Alternatively, if food is plentiful at this stage, diabetes mortality is increased in grandchildren. Other reports come from the Dutch Hunger Winter; mothers who were malnourished during the first trimester gave birth to babies of normal weight, but their babies (next generation) tended to be heavier than normal. This pattern strongly suggest transgenerational epigenetic effects.

The epigenetic modifications are generally cleared on passage through the germ-line. However, some remain allowing some phenotypes to cross into the next generation. In mice the inheritance of epigenetic modifications at the agouti locus of dams results in variation in coat color. These authors speculate, ‘this type of inheritance may be common’. In another mouse study, epigenetic modifications resulting in ‘kinked tail’ was inherited via either maternal or paternal transmission. Also, in Drosophila (fruit fly), environmental stress induces chromatin disruption which is inherited over several generations.

Histone modification and ncRNAs are suggested as the main mechanisms of non-genetic inheritance that persists for multiple generations. DNA methylation may also play a role.

The epigenetic transgenerational effects of chemical toxins have been studied. One rat study demonstrated that gestating females exposed to an industrial fungicide passed on sperm epigenetic alterations leading to adult onset male testis disease. Another, in which gestating females were exposed to hydrocarbons (jet fuel), showed the 3rd generation manifested ovarian disease, obesity and other pathologies.

Rat mothering of pups (high and low LG-ABN) has been mentioned above. The offspring of low LG-ABN mothers who are raised by high LG-ABN mothers, become high LG-ABN mothers and this phenotype transmitted across generations.

A mouse study revealed that postnatal stress of parents leads to depressive-like behaviors, impaired social interactions and increased risky and reckless behavior in offspring, which is then inherited across at least two generations. A review found that stressed rodents became anxious and this unwanted condition could be passed to subsequent generations.

A rat study reported that when mothers/caretakers were experimentally stressed, they maltreatment the young in their care. This led to altered BDNF gene expression in the young, and after growth, altered gene expression in the adult prefrontal cortex. Importantly, transgenerational epigenetic modifications were passed on to subsequent generations. Elevated methylation in the BDNF gene was observed to be inherited by 3rd generation rats born to abused pups.

There are numerous examples of the administration of stimulants and narcotic to rodents resulting in altered behavior in offspring. In mice, paternal cocaine administration results in impaired working memory in female offspring. Again in mice, exposure of mothers to cocaine results in abnormal DNA methylation in the hippocampus of male offspring for up to 30 days of life.
Rat sires allowed unrestricted self-administration of cocaine produced male (but not female) offspring who had reduced tendency to use (decreased reinforcement) cocaine (a finding which runs counter to what is supposed to occur in humans). The proposed mechanism is BDNF promoter acetylation resulted in medial prefrontal cortex.

**Discussion**

A limitation of this paper is that it was written by clinical psychiatrists with modest training in genetics and epigenetics. This need not be a fatal flaw, however, as we are writing for fellow clinical psychiatrists, and we have taken care to accurately present simplified material.

Epigenetics is a revolution in understanding; it adds an ‘extra layer’ to the nature-nurture debate, and promises to throw open the doors to new theory and eventually, improved clinical practice.

Authorities have already suggested the use of enzymes involved in epigenetic mechanism (such as HATs, HDACs and DNMTs) in therapy for alcohol problems. There is also the suggestion that HATs (which increase acetylation) may have a role in the therapy of unwanted fear and PTSD, while HDACs (which decrease acetylation) may be explored as therapy for Alzheimer’s disease.

It is early days, and knowledge is incomplete. For example, with respect to drug addiction, epigenetic modifications have been demonstrated, but it is not yet clear whether these are predisposing or a response factors.

We have used human epidemiological studies to cardiovascular disease to the demonstrate the impact of environmental factors on health. We have highlighted the evidence for epigenetic modification leading to physical disease in rats, and many rodent models of mental disorders and outlined some recent human epigenetic discoveries.

Of enormous interest is that epigenetics gives a molecular explanation for long recognized behavioral responses to childhood adverse events and drug addiction. Also, there is the promise of better understanding other major mental problems including schizophrenia, mood disorder, and borderline personality disorder. The BDNF gene promoter has been suggested as an area of interest in mood disorder, suicide, PTSD, drug addiction, and borderline personality disorder, as well as laboratory animal studies.

We have provided convincing evidence of mammalian transgenerational epigenetic alterations. Epidemiological studies of human nutrition and health suggest transgenerational epigenetic modification.

Of enormous concern is the possibility that transgenerational epigenetic modifications may be common in humans. Should we discover that an adverse environment of child or the adult experience can lead to non-genetically inherited maladaptations or diseases in subsequent generations, humane, social, public health and economic issues will soar. This will call for a redoubling of our efforts to provide a safe world in which all receive ample opportunities.

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BRIEF COMMUNICATION

Alcohol Harm in Malaysia: Always the Right Time to Discuss

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Introduction: Alcohol is a major risk factor for various non-communicable diseases (NCDs) such as cardiovascular related illnesses, liver cirrhosis and cancer. Despite the dangers of alcohol use, there is limited local research available to assist policy and advocacy. This commentary attempts to highlight what is presently available and suggestions to move forward in this field of research and services provision. Methods: A brief report of recent updates is provided for this article. Results and Conclusion: A number of recommendations are provided to assist in deliberating discussions to shape future policies which will improve current available practice and clinical service in the field of alcohol addiction.

Keywords: Alcohol Dependence, Addiction, Prevention

Alcohol is a major risk factor for various non-communicable diseases (NCDs) such as cardiovascular related illnesses, liver cirrhosis and cancer1. Alcohol harm is widely seen amongst those who drink heavily over a period of time. Nevertheless, increase use over short periods such as binge drinking can also lead to medical complications such as acute intoxications, veisalgia, headaches, memory loss and blackouts. Acute heavy alcohol use also has serious social repercussions such as motor vehicle accidents, physical fights, domestic violence, sexual assaults and also high-risk behaviours such as unprotected sexual intercourse1. The United Nations (UN) in 2011 passed a resolution to tackle risk factors for NCDs which include alcohol use through preventive measures2. The resolution was meant to be given priority by all member countries and was only the second time a health issue was discussed. The first was the resolution on HIV/AIDS in 2000. At present 63% of the world populations’ death is the outcome of NCDs and this number is expected to only rise further if no action is taken immediately3. Malaysia is a member of the UN since independence in 1957.

According to World Health Organization (WHO), Malaysia per capita alcohol consumption rises from 0.8 litres of pure alcohol in the years 2003-2005 to 1.3 litres of pure alcohol in the years 2008-20104. In the latest National Morbidity Health Survey (NMHS) 2011, it was reported that 11.6% of those above 13 years old were found to be current alcohol users. Alcohol use was discovered to be highest in those living in
urban areas, amongst Chinese, between ages 20-24 years and surprisingly in those with higher level of income. This was different from other studies which often reported alcohol use to be in those from disadvantaged communities with lower levels of income. A major worry however, was binge drinking where 5.7% of those who did drink alcohol drank in this manner. The binge drinkers studied tended to be older (30-34 years) and were Malays. In Malaysia, Malays are defined to be Muslims and therefore prohibited by law to purchase and consume alcohol of any type. Alcohol dependence on the other hand was found to be small (1.2%) Apart from the NMHS, there is very limited information on alcohol use in Malaysia from a health perspective and even lesser in non-health areas such as cost to properties, accidents and other areas of interest. In spite of these findings, clinical observation often note that Indians are found to be over-represented in terms of medical stabilization and treatment for alcohol complications such as delirium tremens and withdrawal seizure in both the emergency rooms and also clinics. Maniam, 1994 however, did not find this in his study but did concur that a more robust community survey was warranted. Therefore, more studies are needed to investigate current rates to ensure the information captured is accurate.

As a result of the low prevalence of alcohol-related disorders in the national statistics coupled with small numbers of local alcohol prevalence studies, there has been limited regulation towards the alcohol industry. The alcohol industry is still able to advertise in both printed and visual media and host events to promote alcohol use. Although meant strictly for the non-Muslim minority, alcohol use unfortunately is not only confined to the 35% of the population as initially presumed. For the native people in Sabah and Sarawak, a previous study found prevalence of use of the latter to be higher and alcohol dependence was reported to be as high as 30%.

In light of the presently available information and the apparent lack of interest in alcohol harm in Malaysia, the authors are compelled to start this discussion. The platform within Malaysian psychiatry was taken as psychiatry is the major discipline involved with the care of those with substance related disorders and mental illnesses including alcohol dependence. The evidence is slowly pointing towards a possible national crisis especially in Sabah and Sarawak which has the highest numbers of alcohol users. Malaysia is also unique in that alcohol use is not confined to industry produced alcohol but also local brew known as ‘tuak’ in Sarawak and ‘lihing’ in Sabah, both of which have alcohol levels which are still not well studied. Clinical experience in dealing with alcohol-related disorders will show that patients who sought help, or were compelled to seek medical interventions for their alcohol problem consumed cheap liquor marketed with brands such as ‘Thai Song’, ‘Club 99’, ‘7 Seal’, ‘Orang Tua’ and several others. These cheap alcoholic beverages can have alcohol contents up to 40%. These beverages were often cheaper and consumed when unable to afford branded beverages.

Similar to the fight against tobacco use in Malaysia, a similar strategy is needed for alcohol misuse and harm. There must be a plan to increase preventive efforts through restricted sales to non-minors, increase in alcohol taxations and limited sales in specific establishments. There is an opportunity to prevent mistakes made in countries such as New Zealand which allowed alcohol to be sold in supermarkets as a food item when it is known that alcohol
in its pure form is a poison and a substance of abuse\textsuperscript{11}. However, tighter regulation in the sales of alcohol alone may promote the consumption of locally brewed alcoholic beverages and the smuggling of untaxed alcoholic beverages. Therefore, more stringent enforcement is needed as well. Promotional activities also need to be regulated to stop the indirect and direct advertising to minors. One study had reported that 45\% of Malaysian youth had consumed alcohol\textsuperscript{12}. The NMHS methodologically recorded alcohol use amongst those 13 years and above in its survey and therefore there was a possibility that some respondents were underage during the reporting.

Unlike the mistakes made in tobacco control in Malaysia, treatments for current problem alcohol users should start early through locally available services. All clinicians in these services also need to be trained and proficient with the knowledge and experience in dealing with alcohol dependents. It is preferable if more primary care practitioners, especially those in government health clinics, apply the interventions suggested in the guideline to manage alcohol problems at primary care level published by the Ministry of Health\textsuperscript{13}. The guideline uses Alcohol Use Disorders Identification Test (AUDIT) as a screening tool to detect problematic alcohol drinkers and its intervention is based on Brief Intervention (BI) from the WHO. Severe cases, however, need to be referred to centres with specialist care, especially centres with addiction specialist. Ideally management of problematic alcohol drinkers at the referral centres should not only be confined to the department of psychiatry and mental health, but include other medical specialities to work in a more multidisciplinary approach. To achieve optimal multidisciplinary inputs during medical stabilization, these drinkers need to be treated in a specific multidisciplinary ward for patients with addiction and substance disorders. Medical schools in Malaysia can also assist by ensuring all graduates have minimum competency in alcohol treatment provisions as a requirement to graduate as medical doctors. At present, the authors are not aware of this requirement in the 34 available local medical schools.

In order for these efforts to work, there needs to be national involvement under the purview of the Ministry of Health Malaysia working in collaboration with both national and state level stakeholders such as the Ministry of Education and non-governmental agencies. These stakeholders are needed to increase both research and advocacy in alcohol use. The national policy already available should be made known to all relevant stakeholders to ensure smooth implementation of local policies in the country\textsuperscript{1}.

Lastly, it is imperative that discussion on alcohol use is limited to alcohol misuse so as to not stigmatise alcohol users who drink within the recommended limits. Nevertheless this discussion needs to start immediately before alcohol misuse increases further as Malaysia urbanizes and moves towards a high-income nation. As our local studies have found, an increase in income is associated with increasing harm in the context of alcohol and therefore every effort must to be made to ensure that Malaysians are protected and assisted should the need arises.

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