

## **CHALLENGES IN CASE MANAGEMENT OF PERSONS WITH MENTAL DISABILITIES IN MALAYSIA**

*(Cabaran Pengurusan Kes Orang Kurang Upaya (Oku) Mental Di Malaysia)*

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### **ABSTRACT**

Case management of Persons with Disabilities (PWD) particularly the mental category has been scarcely studied in Malaysia. With mental illness rapidly growing into a public health issue, more research especially in the aspects of case management is needed. In relation to that, this paper aimed to explore on the challenges in case management that case workers for persons with mental disabilities (PWMD) faced in Malaysia. This qualitative study conducts in-depth interviews twice with 10 case workers from Medical Social Work Department and Social Welfare Department. Data were analysed thematically using content analysis method. The study discovered that challenges arise were negative perception towards PWMD, lack of specialized trainings, and lack of effective collaborations between agencies. The findings suggest that the Health Ministry and Welfare Department should enhance collaboration between them in getting their resources such as information and manpower together in fulfilling the needs of PWMD. On top of that, the study highlights the importance of case workers' roles in brokering between the agencies in order to increase client functionality in society. This paper is important for policy makers to take into account the needs and the capacity of the PWMD and also caseworkers to ensure the effectiveness of both welfare and health services. Thus, the case management services for persons with mental disabilities will be improved which are aligned with Malaysia's social work competency standards.

**Keywords:** Persons with Mental Disabilities; Case Management; Caseworker; Social Work; Challenges

### **ABSTRAK**

Kajian mengenai pengurusan kes OKU mental masih belum cukup di Malaysia. Dengan isu penyakit mental semakin menular sebagai isu kesihatan awam di Malaysia, lebih banyak kajian terutamanya dalam pengurusan kes diperlukan. Sehubungan dengan itu, makalah ini bertujuan untuk meneroka cabaran pengurusan kes yang dihadapi pekerja kes orang kurang upaya (OKU) mental di Malaysia. Kajian kualitatif ini melakukan temu bual secara mendalam sebanyak dua kali dengan 10 informan yang merupakan pekerja kes dari Jabatan Kerja Sosial Perubatan dan Jabatan Kebajikan Masyarakat. Data dianalisis dengan menggunakan kaedah analisis kandungan dengan mengeluarkan tema. Kajian ini menemui bahawa cabaran yang muncul adalah persepsi negatif terhadap OKU mental, kekurangan latihan yang khusus, dan kurangnya kolaborasi yang berkesan antara agensi. Penemuan menunjukkan bahawa Kementerian Kesihatan dan Jabatan Kebajikan Masyarakat perlu meningkatkan kerjasama antara mereka

dalam mendapatkan sumber seperti maklumat dan tenaga kerja bersama bagi memenuhi keperluan OKU mental. Lebih-lebih lagi, kajian ini menunjukkan pentingnya peranan pekerja kes dalam pembrokeran di antara agensi untuk meningkatkan fungsi pelanggan dalam masyarakat. Kertas kerja ini penting bagi pembuat dasar untuk mengambil kira keperluan dan keupayaan OKU mental dan bagi memastikan keberkesanan perkhidmatan kebajikan dan kesihatan. Oleh itu, perkhidmatan pengurusan kes untuk OKU mental akan ditingkatkan sejajar dengan standard kompetensi kerja sosial Malaysia.

**Kata kunci:** OKU mental; pengurusan kes; pekerja kes; kerja sosial; cabaran

## **INTRODUCTION**

In accordance to the Disability Act 2008, Persons with Mental Disabilities (PWMD) can be defined as individual that has been under psychiatric treatment for at least two years. Their state of social, cognitive, and behavioral functioning also need to be assessed and confirmed by a psychiatrist. They are entitled to have the disabled card upon adhering to these criteria which carries benefits such as public transport discounts, medical facilities and medicine discounts, disability allowance and also tax exemption (Prime Minister's Department, 2017). Examples of the type of illness associated with PWMD are Schizophrenia, Mood Disorder and Organic Mental Disorder.

Currently, mental health illnesses are affecting more and more Malaysian and the number is rising on the contrary to the rate of the numbers of services and treatment for mental health illnesses in Malaysia. Statistically, according to the National Health and Morbidity Survey (2015), 29.2 % of population aged 16 and above are expected to have some sort of mental health issues. The number has increased significantly from 10.7 % in 1996 and 11.2% in 2006. It is expected that mental illness will be the second biggest health issues in Malaysia by 2020 after heart diseases.

In addition, females are seen to be slightly more affected compared to males with 30.7% affecting female and 27.6% affecting males. Prevalence in children aged 5 to 15 years old is 12.1 %. In terms of the affected cities the Capital of Malaysia, Kuala Lumpur has the highest percentage of prevalence with 39.8%. The number of psychiatrist in Malaysia is 360 in both public and private sectors which reflects the current ratio of 1:200,000 to the population as opposed to the number suggested by WHO which is 1:10,000 (Ministry of Health Malaysia, 2015). Plus, the current population of social workers in Malaysia who work with PWMD still cannot be identified but 276 medical social workers were recorded in the year 2015 in Malaysia (Bernama, 2015).

Officially, Malaysia has an approved mental health policy. The policy was revised in 1998. In the general health policy, mental health was not mentioned. The latest mental health plan was revised in 2002 which included in it the transfer of services and resources into the community mental health centers and also included the integration of mental health care and services into the primary care (World Health Organizations, 2011). Malaysia's mental health policy grasp the ideas that the future of mental health care is in the community.

Furthermore, the statistics in table 1 shows that persons with mental disabilities (PWMD) comprised of eight percent which are 29,403 from the total 365,677 of the total percentage of the Person with Disabilities (PWD) in Malaysia (Jabatan Kebajikan Masyarakat, 2015).

**Table 1:** People with Mental Disability (PWMD) Registration According to Age

Age Group (Years)	Registration
Less than 6	2
7 - 12	12
13 - 18	154
19 – 21	326
22 – 35	7,268
36 – 45	9,103
46 – 59	9,698
60 above	2,840
Total	29,403

Source: Jabatan Kebajikan Masyarakat (2015)

A rise in the number of registrations can be seen from the age group of 19-21 years and 22-35 years. In early adulthood age are said to be at risk for mental illness and this can be attributed to their adaptation to start their career or adapt to a new environment in work or in their studies (Hagell, Coleman and Brooks 2015). Besides, in Malaysia, the actual number still cannot be identified since the registration of the disabled is voluntary, thus the total number of persons with mental disabilities is still unidentified (Mohd. Suhaimi et al. 2012; Steffen 2009).

According to a previous study on case management, concept of case management has grew over the years and embedded into routine clinical practice. However, concerns has been raised in incorporating basic case management principles due to the difference in the social care and health systems (Holloway and Carson, 2001).

Originally case management for the mentally ill was constructed in the United States of America (U.S.A) to provide continuity in their care (Teoh 200). In London, related authorities find it more suitable to call case management for the mentally ill as “care management” (Great Britain Department of Health, 1989). This is because of the abundance of aspects involving care in the case management of the PWMD.

Furthermore, literature shows that in case management of PWMD one of the preferred models in the United Kingdom is the administrative model where the care management staffs liaises and brokers for them services. This model prioritized coordinating and purchasing care which showed their approach as an independent non-provider. The rationale behind the approach was to prevent conflict of interest but concerns were raised regarding their quality of service and their role as an advocator. PWMD clients found this model as ineffective and intolerable (Huxley and Warner, 1992). Evidence also shows that these approach leads to an increase of bureaucracy (Lewis, Bernstock, Bovell, and Wookey, 1997).

Besides the administrative model, there is also a British approach to care management of PWMD. The British approach links with other services and directs clients to the necessary services according to their needs (Onyett, 1992). In addition to that, the fundamentals of this model is to provide continuity of care such as enabling clients to have an organised and an uninterrupted involvement with services for as long as the clients requires (Bridges, Davenport, and Goldberg, 1994; Shepherd, 1991). Hence, the care manager in this approach was tasked with managing direct-care staff and coordinating them.

As part of the theoretical part of the study, the researchers adapted the Person-in-Situation approach. The researcher suggested that social workers as case workers can incorporate philosophical understanding and the relevance of objective and subjective

phenomena which can form a comprehensive approach to human and also environment (Cornell 2006). Thus, this approach was suitable to be applied in the study.

In this paper the involvement of the Social Welfare Department and the Health Ministry is focally discussed especially in terms of their microsocial services to PWMD. One of the questions that is raised from the study are what are the challenges that the case workers faced working with the PWMD. The aspects of case management for PWMD from both departments are extracted and the case workers challenges are highlighted. This is aligned with the study aim which is to explore the challenges that the case workers faced in case management of the PWMD. Thus, micro-issues revolving PWMD in case management are highlighted in this study so that it can be addressed as a way of moving towards the better future of PWMD.

## **METHODOLOGY**

This qualitative study was designed using the content analysis inductive method. It is done with a case-study approach. The study underwent several processes of content analysis which included open coding, creating categories and abstraction (Elo & Kynga, 2007). This paper takes the informant's experience as a caseworker for persons with mental disabilities (PWMD) as a case study to explore the support system of the mentally disabled in Malaysia.

### **Research Samples and Location**

Five informants were medical social workers from Medical Social Work Department who covered medical social work and the other five were community development officers from the Social Welfare Department who were working more as generalist social workers working in units such as productive welfare, institutional care, disability unit, and also from the enforcement department. All 10 of them were selected among assistant community development staffs, assistant community development officers and community development officers from grade S17 to S52 who have at least two years of working directly with the mentally disabled. All of them have academic qualifications in social work or experience related to social work field of study.

Furthermore, the informants were chosen from Klang Valley area as the study area because it was an area under the Federal Territory of Kuala Lumpur and Selangor which showed the highest number of people with mental disability in Malaysia (Jabatan Kebajikan Masyarakat, 2015).

### **Process of Data Collection and Analysis**

In selecting the informants, purposive sampling technique was used. This study conducted in-depth interview twice with each informants to ensure the saturation of the data (Mack, Woodsong, McQueen, Guest, & Namey, 2005; Willig, 2013). Open-ended and semi-structured questions were used as the foundation of the qualitative tools. Informed consent was obtained from each of the informants. This study was done with the approval of the welfare department and the medical social work department in which some of the respondents were from. Observations and notes were taken by the researcher during each of the interview. Data gathered were recorded and transcribed. Verbatim transcripts were made to ease the analysis and data organization. Data were analyzed using NVIVO 10.

This study used 6 stages of thematic analysis in accordance to Clarke and Braun (2006) which were, data collecting process which involved making notes and early observations and rereading transcriptions, coding to simplify the identification process, identifications of key themes from similar traits in the data, checking the relevance of the themes, describing the themes in-depth to align with the research objectives and finally forming a report from the analyzed themes to further support the data (Clarke & Braun 2006; 2013). The validity and reliability of the study were conducted using peer review and review techniques. Peer review added to the credibility of the study with revisions made by individuals who were in the same field that can reduce the bias in an unprejudiced study of researchers (Golafshani 2003; Noble & Smith 2015).

## **RESULTS AND DISCUSSIONS**

Results of the study has recognised three main challenges that the case workers faced in case management of the PWMD. The challenges were negative perceptions towards PWMD that makes it difficult for case workers to manage their cases. Secondly, was the lack of specified training specifically in training workers working with PWMD. Lastly, was the lack of collaboration between agencies that cater for PWMD which creates limitations for case workers to manage cases effectively. The study also unveils current scenarios of PWMD in Malaysia as it revolves more around socio-economic factors and homelessness.

### **Current Scenarios of Persons With Mental Disabilities**

In reflecting the current scenario of the mental health in Malaysia, the informants shared their insights regarding PWMD in Malaysia. The study discovered that, most youth were involved in drug-induced cases as a big part of PWMD were detected as part of the homeless and vagabonds. Verbatim below demonstrated this:

*“Most of the PWMD cases especially the young ones, are addiction to drug cases”*  
(Informant 1 – 2 years of experience).

*“Most of the mentally disabled are identified to be squatters. We found out when we receive report on homeless people and when we bring them for medical check-up we found that they are mentally disabled, some of them even have their OKU card (disabled benefits card)”*  
(Informant 5- 5 years of experience).

Furthermore, in the homes of the PWMD, level of hygiene of their house was typically low, and the arrangements of the household items were badly disorganized (Fatimah, Nur Saadah, Mohd Suhaimi, and Nor Jana, 2013). This unkempt situation reflects the importance of having families or any other type of support in order to assist the lives of a recovering PWMD in living a proper and productive lifestyle.

*“In average five new cases a day in the city area which could indicate pressure from family from an economical aspect”*  
(Informant 4 – 4 years of experience).

Based on the above verbatim, Informant 4 stated that currently in average up to five PWMD cases a day can be registered. Informant 4 worked in the welfare department in one of the busiest city, she mentioned that most of the clients become mentally disabled due to family pressure and pressure from the economy. This proved that with the increased living cost, the number of PWMD is also on a rapid rise. This is supported with the data stating that Kuala Lumpur has the highest prevalence rate of mental health related cases (Ministry of Health Malaysia, 2015).

## **Challenges in Case Management**

### **Negative Perceptions towards Person with Mental Disabilities**

In Malaysia, most people still associate mental health with mental illness due to the stigma attached to the individuals with mental illness (Hanafiah & Van Bortel, 2015; Knox et al. 2013; Chong, Mohd Suhaimi & Er, 2013). The situation proves that negative perceptions on PWMD are still at large. Hence, this may suggest that social exclusion occurs to them. This situation is not helped by the social exclusion that occurs to the PWMD which do not include them in process of development and decision making (Islam, 2015).

Negative perceptions and discriminatory attitudes does not only affect the PWMD but also their families (Robinson, Rodgers, & Butterworth, 2008). Families also face discrimination and negative perceptions which makes it difficult for PWMD to obtain proper recognition and empowerment as described in "The United Nations' Convention on the Rights of Persons with Disabilities" (CRPD) (United Nations, 2006).

Besides, a recent study by UNICEF has discovered that mental disabilities are the most stigmatized among all of the disabilities. A total of 58% of the survey refuses to live in the same neighbourhood with a child with mental disabilities (UNICEF Malaysia, 2017). This prove that PWMD are clearly discriminated in the country. The verbatim below demonstrated the negative perceptions faced by PWMD from their family members which forced them to live independently on their own

*"The main issue is when there's no family support at all. So the mentally disabled has to survive on their own, for those with kids they have to raise them on their own. This breeds other complications into mentally disabled cases"*

(Informant 4 – 4 years of experience).

*"Families don't see the need for the PWMD to receive continuous treatment, sometimes the family do understand but the clients won't"*

(Informant 6 -10 years of experience).

Family is primarily the first line of defence for every individual and due to that it is essential for family to learn how to provide support, praise and encouragement (Kaur & Arora, 2010). Failure to do this could result in lack of no supportive measures for PWMD as mentioned in the above verbatim. This potentially could result in high stress levels for families, and not conducive family atmosphere for the PWMD's recovery (Kaur & Arora, 2010).

As mentioned, negative attitudes and perceptions towards mental PWMD may indeed signalled stigma attached to the PWMD. Any attempts to create barriers, denying dignity and demanding social integrity and equality (UNICEF, 2008) and maintaining a 'crippling

environment' can be associated with stigma (World Health Organization, 2011). PWMD are vulnerable to systemic isolation from the mainstream social, cultural and political opportunities (UNICEF, 2008). The isolation will only jeopardize their recovery process and restrict their potential to have a productive lifestyle.

In addition to that, this study also identified negative perceptions coming from the mental health professionals through the labels they used to describe the place where PWMD were located. The usage of inappropriate words to describe the disabled or anything associated with the disabled indicated negative connotations and stereotypes towards Persons with Disabilities (PWD) (Norazit, 2010). The verbatim below shows negative perceptions from the medical social worker from a psychiatry hospital in Malaysia.

*“Because we are considered working in a “crazy” hospital. So the question is how can we cope working in this “crazy” hospital”*

(Informant 1 – 2 years of experience).

Moreover, this study may have discovered self-stigma within the PWMD, they refused to return to their family as they have stigma attached to themselves. They think that they do not deserve to have a sense of belonging. The verbatim below proves the statement.

*“In some cases the PWMD refuse to return to their home, they claimed that they know their family are better off without them, but still they send their family money gained from the welfare department”*

(Informant 1 - 2 years of experience).

Thus, the negative perceptions attached to the PWMD and their families leave them vulnerable for exploitation. Negative perceptions that PWMD are prone to violence has to be stop as all human being regardless of abilities are capable of being aggressive. The verbatim below prove that even service providers are associating PWMD with violence.

*“PWMD are said to be aggressive, as to only the police and health officials are equip with the tools to apprehend them”*

(Informant 5- 5 years of experience).

Education and awareness is one of the ways to combat this issue. As for the service providers working with PWMD, more specialized training is needed to ensure that they are given the right tools to properly empower the PWMD. Having said that, some government agencies, have started to combat these perceptions by not wearing uniforms on duty to help reduce discriminations towards the mentally disabled and their families (Fatimah et al., 2013).

### **Lack of Specified Training**

Aside from stigma and discrimination, another challenge that was discovered in the study was the lack of specialized training for the families, service providers and also individuals around PWMD. In cases where PWMD were living with their families they were often living in an unproductive state such as being caged or locked away in the rooms. These situations occurred because families who are willing to care for their mentally disabled family members often find themselves lacking the training and education (Fatimah et al, 2013).

*“A lot of factors, families said they are busy, they don’t have the skills to care for the PWMD, it’s hard for them to do it”*

(Informant 3 – 2 years of experience).

The verbatim above was from one informant who shared his experience conversing with families of PWMD. The families mentioned their lack of skills and lack of training for not caring for PWMD. The informant also admitted that currently they did not have any specific training especially for families to care for the PWMD.

*“The psychiatric department gave out a course but it’s only more on what are the psychiatry illness. No training regarding how to care or manage the mentally disabled. Plus we are more in a hospital setting so we focus more on diagnosing illness, about treatment”*

(Informant 2- 2 years of experience).

*“Expertise especially in terms of training there has not been any, we are not trained in handling the PWMD”*

(Informant 5 – 5 years of experience).

Furthermore, as for the service providers, the training provided towards the caseworkers were just knowledge involving the illness and the treatment. Other training involving how to care for the PWMD or how to interact with PWMD was not provided.

The verbatim below states that could indicate the result of service providers not being trained specifically for the task. Values and ethics should be ingrained among service providers especially when working with disadvantaged groups such as the PWMD’s. The lack of training especially involving values and ethics in dealing with clients who were from marginalized community could cause other complications such as verbal or physical abuse from the service providers.

*“Some of the service providers have contrasting values, they didn’t respect the client, they are harsh with them”*

(Informant 5 – 5 years of experience).

As a conclusion, awareness has been raised in the mental health field which could open the route to more effective interventions. However, there are a lot of room for improvement especially in terms of specialization in training for PWMD and individuals or communities around them. As mental health slowly emerges as a public health issue in the country as mentioned before, the mentally disabled has to be prioritized in alignment with the state of our country move towards a developed country. A collaborative effort to provide holistic training for families, service providers and the PWMD themselves would surely benefit the clients.

### **Lack of Effective Collaboration**

The study discovered that collaboration existed between the agencies in providing the services for PWMD. However, a comprehensive collaboration consisting of multidisciplinary agencies were not present. Only unofficial collaboration as mentioned in the verbatim below were currently present:



*“The only existing collaboration that we have normally are the ones with the authority bodies (police department), because sometimes families doesn’t want to cooperate. The collaboration is not an official one, it is more like a supportive gestures from other agencies”*

(Informant 2 - 2 years of experience).

The study also recognized the potential collaboration that has not been built especially in terms of care management or case management. The care management of PWMD was divided into two. Health ministry is responsible to diagnose and confirm PWMD and the social welfare department will serve as the practitioner. Resources in terms of placement and staffs can be saved if collaboration was developed especially from these two main bodies that catered for PWMD. The verbatim below indicated there was a lack of collaboration between the two agencies especially in terms of care. The existing services and a lack of integration of the two bodies created difficulties to provide services for the client holistically.

*“There is collaboration but not in terms of care”*

(Informant 3 – 2 years of experience).

*“Only collaboration we have is we call the social welfare department officers to share regarding the benefits they provide for the Person with Disabilities (PWD). It so that we medical social worker know the criteria to be registered as PWD”*

(Informant 2 – 2 years of experience).

An effort to collaborate using the normal procedures often proved difficult especially in urgent cases. This lack of collaboration also proved to have a waste of time especially in sharing simple information such as whether the client has been registered there before.

*“One problem in liaising the clients to the health officials is the procedure, they don’t make it easier for us to send the PWMD for a check-up or check whether they have been registered in the hospital”*

(Informant 5 – 5 year of experience).

On the other hand, because of the lack of interchanging roles between the agencies, they have the tendencies to delegate their responsibilities by claiming it was not their responsibility. Besides, other officials such as service providers from the law department will question their expertise on why the welfare department were handling cases of PWMD as featured in the verbatim below.

*“Once I faced a situation where I called my superior officer regarding and I ask him what should we do with the PWMD, he just replied for me to send the PWMD to the health officials”*

(Informant 5– 5 years of experience).

*“Plus they are also cases where in the court of law where lawyers or magistrate would question why we from the welfare department are handling cases of the PWMD, they would often question us whether mental disabilities are considered to be in our field”*

(Informant 5 – 5 years of experience).

Collaboration needed to be widely spread and announced to make sure that all related services were well informed of it. Lack of training was also visible especially in other related officials as they failed to acknowledge the relation of certain agencies. Having said that, with Malaysia rapidly developing we are well aware that these agencies are facing tonnes of workload and that makes working towards collaboration a much more ideal solution. Sharing the workload and working for the best of PWMD will surely demonstrate Malaysian capabilities in managing one of the most marginalized communities in the world.

Effective and inclusive collaboration are essential to be the foundation of services especially for the service providers. Even though it is difficult to manage at first but it will help us to fully utilise our resources especially in terms of manpower, expertise and information.

## **CONCLUSION**

In summary, this study suggests that the Health Ministry and Welfare Department should enhance collaboration between them in getting their resources such as information and manpower together in fulfilling the needs of PWMD as they are the current key agencies for PWMD. In addition, their approach in services has to revolve more around the client. Limitation of the study is that the researcher did not acquire insights and perspective of the PWMD clients to complement the challenges of the case workers in case management. Perhaps this could be an opportunity for research as the PWMD perspectives on their case management is equally important to the insights of case workers who are delivering the services. The role of case workers' in brokering between agencies and PWMD has to be enhanced in order to increase client functionality in society. That can be achieved through building good rapport between the case workers and PWMD. Future studies should be done which involve identifying whether good rapport has been widely establish in case management between the service providers and the clients.

As rapport proves to be the determinant of the success of the intervention, building good rapport is important. This is the basis of an effective intervention that consists of adaptation of social work practice and case management models that prioritize the client's future, welfare and well-being (Brahim et al., 2015). This paper is important for policy makers to take into account the needs and the capacity of the PWMD and also caseworkers to ensure the effectiveness of both welfare and health services. Thus, the case management services for persons with mental disabilities will be improved in alignment with Malaysia's social work competency standards. Furthermore, in this country, integrating PWMD as a progressive member in the community is one of the primary goals that has to be achieved step by step. Most mental health related department in the health ministry and social welfare department are also working with and towards the community to reach this vision.

In a nutshell, to conclude, case management on its own is not an effective way to treat mental illness (Holloway and Carson, 2001). Thus, increased interactions with other parties such as the government and community will further increase their awareness and understanding on the challenges that the case workers of the PWMD face. By doing that we can empowered PWMD and we can next focus on what they can contribute to the country instead of just focusing on what is disabling them. Adherence to National Social Work Competency Standards is a must to ensure the quality of services for case management of PWMD.

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