



UNIVERSITI PUTRA MALAYSIA

***DETERMINANTS OF PARTICIPATION
IN COMMUNITY-BASED REHABILITATION PROGRAMMES
AMONG CAREGIVERS OF DISABLED CHILDREN***

FARIDAH MOHD SAID

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By

FARIDAH MOHD SAID

**Thesis Submitted to the School of Graduate Studies, Universiti Putra Malaysia,
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Caregivers' participation in rehabilitation is an active involvement in an acceptable course of a rehabilitation intervention programme to produce a desired therapeutic outcome, prevent complications arising from the disability and eventually improve the quality of life (QOL) of children with disabilities. It involves elements of motivation to stay adhered throughout the process, in which the majority of clients do not. The Health Belief Model (HBM) postulates reasons for none adherence to rehabilitation programs closely related to lack of motivation, barriers to treatment and ineffective self-efficacy to perform the required health behaviour. Permanent disability acquired by children with disabilities (CWD) has negative social, financial and QOL implications. Caregiver need to stay at a high-level of participation within rehabilitation programmes in community-based rehabilitation centres (CBRC) in the course of

QOL and importantly be inclusive in the community. The caregivers of CWD are an essential pillar to ensure full participation in the CBR programme. However, previous studies reported low participation to CBRC among caregivers which has long term negative implications for the CWD, their caregiver and the community.

This study examined the determinant factors influencing caregivers' participation in community-based rehabilitation programmes. The direct and mediating variables been explored. This is a correlation study with the HBM used as a research framework. Fourteen CBR centres were randomly selected using stratified random sampling. Data was collected using a self-administered questionnaire from 299 randomly selected caregivers from CBRC who met the inclusion criteria. Data analysis employed descriptive statistic, Paired T-test, ANOVA and Structural Equation Modeling (SEM) to examine direct and mediating variable to answer the research questions.

The findings of the study showed that the average age of caregivers was 41.9 years. The largest proportions (36.5%) were among adults aged (40-49 years), and most are women (70.2%). The average age of CWD was 10.2 years. Finding revealed that more than one-fifth (22.7%) of the CWD are diagnosed as Cerebral Palsy, Down syndrome (21.4%), and over a quarter (25.8%) classified in other categories of disabilities. The majority of caregivers 59.5% revealed of low level of participation, while only 52.8% perceived that disability of the child in the low, "cues for actions" was low (53.2%). More than half of respondents (60.5%) perceived threat of disability, while 54.5% of them perceived benefit from the

CBR and a total of 51.2% perceived barrier to be involved with the CBR. Cues to actions were statistically significant ($p < 0.05$) determinative of caregivers participation in CBR in the range of moderate effect size.

Findings of the test T-Test and ANOVA showed significant differences in severity of disability between gender, age, and differentiation of severity of disability before and after the intervention program CBR at $p < 0.05$ with effect size from large to small depending on the disability domain. Results showed that younger age and gender have different results with a significant recovery. Structural equation modeling analysis (SEM) was conducted to test the proposed mediation model. The model shows a direct and mediation effect between the relationship perceived severity illness, cues for actions, coordinated care, implementation of care and self-efficacy with caregivers' participation through perceived threat, perceived benefits and perceived barrier. This model showed a good fit to the data of the study ($p < 0.05$, $X^2/df = 1.785$, CFI = 0.909, IFI = 0.910 and RMSEA = 0.055).

Further inspection revealed that result from SEM showed that cues for action has a direct effect on caregivers' participation to CBR, while no significant mediation effect in relationship between participation with perceived severity, cues for actions, coordinated care, implementation of care through perceived threat, benefit and barrier.

In conclusion, findings indicate that there is a direct effect of "cues for action" on caregiver participation in CBR. Caregivers' perceived that CBR programme

significantly reduced the severity of disability, thus, improved the quality of life of CWSN. Cost-effective strategies must be formulated to increase the participation among caregivers. Improve information through social support networks helps to enhance knowledge and self-efficacy to increase participation among caregivers. Implementation of the program should be coordinated to tailor with caregivers and CWD needs to overcome barrier and enhanced perceived benefit of participation. This study provides implications for CBR programme planner and providers with regards to the importance of information in enhancing participation.



Abstrak tesis yang dikemukakan kepada Senat Universiti Putra Malaysia
sebagai memenuhi keperluan untuk Ijazah Doktor Falasafah

**PENENTU PENGLIBATAN DALAM PROGRAM PEMULIHAN DALAM
KOMUNITI DIKALANGAN PENJAGA
KANAK- KANAK KURANG UPAYA**

Oleh

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JUNE 2012

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Penglibatan penjaga dalam program rehabilitasi adalah pembabitannya secara aktif dalam program intervensi pemulihan bagi menghasilkan kesanan terapeutik positif, mengelakkan komplikasi akibat dari kecacatan dan akhirnya meningkatkan kualiti kehidupan yang lebih baik bagi Kanak-

Kanak Kurang Upaya. Ianya melibatkan elemen motivasi untuk kekal patuh sepanjang proses rehabilitasi, di mana majoriti klien gagal. "Health Belief Model" (HBM) mempostulasikan sebab ketidapatuhan adalah berkait rapat dengan kurang motivasi, halangan untuk mendapat rawatan dan efikasi sendiri ("self-efficacy") rendah untuk menjalankan tingkah laku kesihatan yang diperlukan. Kecacatan kekal yang dialami oleh Kanak-Kanak Kurang Upaya (KKU)

memberiimpak yang negatif dari aspek sosial, kewangandankualitikehidupan. Penjagamerkamemerlukanpenglibatan yang tinggidalam program rehabilitasidanintervensi yang dijalankan di PusatPemulihanDalamKomuniti (PDK) bagimencapaikualitikehidupan yang baikdanseneterusnyaditerimasebagaiahlimasyarakat. Penjaga KKUmerupakantunjangutama yang menentukanpenglibatansepenuhnyadalam PDK. Walaubagaimanapun, banyakkajianterdahulumelaporkanpenglibatanpenjaga di PDK sangatberkurangan, di manaakhirnyamemberiimpaknegatifmasapanjanguntuk KBK, penjagadankomuniti.

Kajian ini mengkajifaktorpenentuyangmempengaruhipenglibatan penjagadalam programpemulihandalam komuniti. Pembolehubahlangsungdanpengantarajugaditerokai. Iniadalahsatu kajian korelasidenganHBM yang digunakansebagai kerangka penyelidikan. Empat belas pusat PDK telah dipilih secara rawak melalui persampelan rawak berstrata. Data dikumpulkan menggunakan soal selidik yang diisidiri daripada 299 penjagayang memenuhikriteria dan menjawab semua soalan kajian. Analisis datamenggunakan statistik deskriptif, ujian "Paired T-Test", ANOVA dan Model Persamaan Struktural (MPS) untuk mengkaji kesan langsung dan pengantara pemboleh ubah untuk menjawab persoalan kajian.

Dapatankajian menunjukkan purata umur penjaga adalah 41.9 tahun. Propositer besar (36.5%) adalah dalam kalangan dewasa berumur (40-49 tahun) dan kebanyakannya adalah wanita (70.2%). Purata umur KKU adalah 10.2 tahun. Di dapat lebih satu per-lima (22.7%) dari KKU dikategorikan di bawah kecacatan Cerebral

Palsy, *Down Syndrome* (21.4%), dan lebih satu per-empat (25.8%) dikategorikan dalam kecacatan lain-lain. Majoriti 59.5 % penjaga di bawah paras penglibatan yang rendah manakalanya 52.8% menganggap kecacatan anak (*perceived severity of disability*) di peringkat yang tidak teruk, “*cues for actions*” adalah rendah (53.2%), merasatercancam di sebabkan kecacatan (*perceived threat*) tinggi 60.5%, manakala 54.5% “*perceived benefit*” dari PDK dan seramai 51.2% merasakan “*perceived barrier*” untuk terlibat dengan PDK. Kiu untuk tindakan (“*Cues for actions*”), merupakan hubungan langsung yang signifikan ($p < 0.05$) penglibatan penjaga dalam PDK dengan saiz kes dalam julat sederhana.

Penemuan hasil ujian T-Test dan ANOVA menunjukkan perbezaan yang signifikan dalam keterukan ketidakupayaan antarajantina, umur, perbezaan sebelum dan selepas program intervensi dan PDK pada $p < 0.05$ dengan kesan saiz dari besar dan kecil bergantung pada domain kurang keupayaan KKU. Hasil kajian menunjukkan umur yang lebih muda dan jantina lelaki mempunyai perbezaan hasil pemulihan yang signifikan. Analisis Model Persamaan Struktural (MPS) telah dijalankan untuk menguji model pengantaraan yang dicadangkan. Hasil analisis model menunjukkan kesan langsung dan perantaraan di antara hubungan “*perceived severity*”, “*cues for actions*”, “*coordinated care*”, “*implimentation of care*” dan “*self-efficacy*” dengan penglibatan penjaga melalui “*perceived threat*”, “*perceived benefit*” dan “*perceived barrier*”. Model didapati sepadan dengan data kajian ($p < 0.05$, $X^2/df = 1,785$, $CFI = 0,909$, $IFI = 0,910$ dan $RMSEA = 0.055$).

Penelitian lanjut mendedahkan bahawa hasil dari MPS menunjukkan bahawa “cues to action” mempunyai kesan langsung ke atas penglibatan penjaga di PDK, manakala tidak terdapat kesan pengantara yang ketara dalam hubungan antara penglibatan dengan “perceived severity” “coordinated care” “implementation of care” dan “self-efficacy” yang terselaras, melalui ‘perceived threat’, “perceived benefit” dan “perceived barrier”.

Kesimpulan hasil kajian ini menunjukkan bahawa terdapat kesan langsung “cues for action” ke atas penglibatan penjaga dalam PDK. Dari persepsi penjaga, Program PDK secara signifikan dapat mengurangkan keterukan kecacatan, dan seterusnya beranggapan dapat meningkatkan kualiti kehidupan. Strategi yang lebih kos-efektif perlu dirangka untuk meningkatkan penyertaan kalangan penjaga. Meningkatkan maklumat dan rangkaian sokongan sosial dapat meningkatkan pengetahuan dan efikasi diri adalah merupakan satu strategi dalam meningkatkan penyertaan kalangan penjaga. Implementasi program perlu diselaraskan agar bersesuaian dengan keperluan penjagaan KKU bagi mengatasi ‘perceived barrier’ dan memurnikan “perceived benefit” dalam penglibatan.

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APPROVAL

I certify that a Thesis Examination Committee has met on 14 May 2012 to conduct the final examination of Faridah Binti Mohd Said on her Doctor of Philosophy thesis entitled “Determinants of Participation in Community Based Rehabilitation Programme Among Caregivers of Disabled Children” in accordance with Universities and University Colleges Act 1971 and the Constitution of Universiti Putra Malaysia [P.U. (A) 106] 15 March 1998. The Committee recommends that the student be awarded the Doctor of Philosophy.

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DECLARATION

I declare that the thesis is my original hard work except for quotation and citation, which have been duly acknowledged. I also declare that it has not been previously or currently submitted for any other degree at UniversitiPutra Malaysia or any other higher institutions.

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Date: 4 June 2012

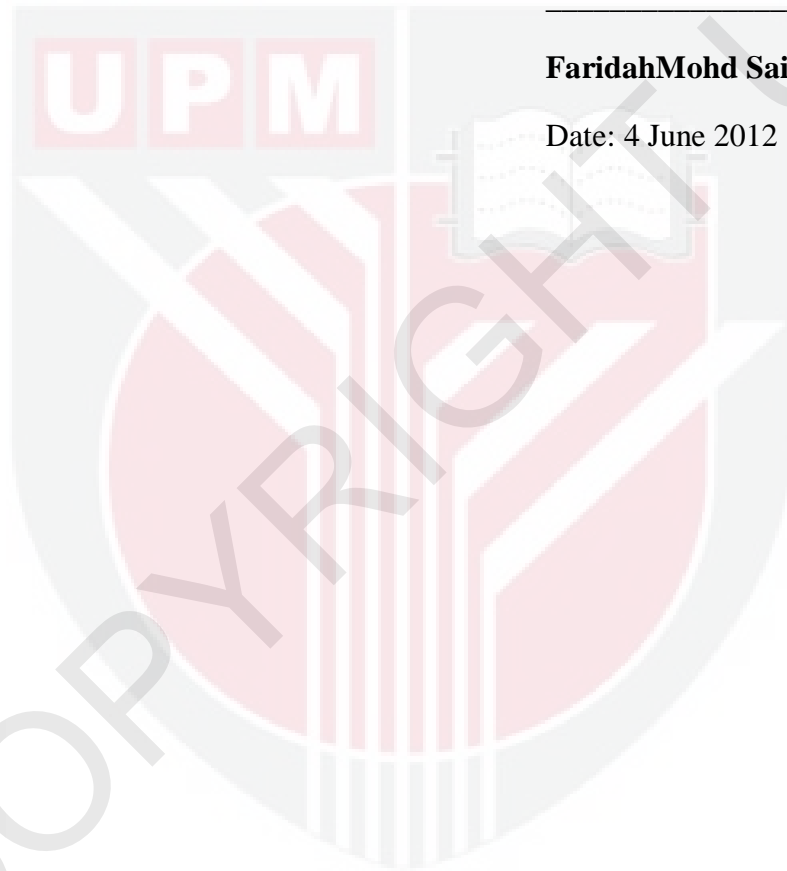


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