Research Report

of

Survey study on carers with a relative suffering from mental illness

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Content

Survey study on carers with a relative suffering from mental illness：

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Introduction

In Hong Kong, the number of people suffering from mental illness is increasing. According to Hospital Authority (HA), the total number of patients receiving various psychiatric services (including inpatient, specialist outpatient, day hospital and psychiatric community services) provided by HA was increased by 26.7% from 147,557 in 2008 to 186,907 in 2012 (Legislative Council, 2012). It is estimated that around 170,000 families having to care for their family members suffering from mental illness in Hong Kong.

Carer's Burden

Taking care of relatives with disabilities is not an easy task. A number of studies have investigated the burdens of caregiving faced by carers who took care of their mentally ill relatives. Studies have revealed that issues of safety and possible violence of the ill individual toward self and other, excessive demands and high dependency toward carers, night disturbances, embarrassing behaviors, symptomatic behaviors, worries about the future, and uncooperative attitude leading to conflicts and family hardship were commonly reported as carers' subjective burdens (e.g. Baronet, 1999).

In Hong Kong, Wong, Lam, Chan, and Chan (2012) conducted a cross-sectional survey in which 276 family members of persons with mental illness were interviewed. The results show that the most highly rated burdens experienced by respondents were "difficulty handling bizarre and disturbing behavior", "difficulty managing fluctuating emotions of ill relatives" and "difficulty handling suicidal thoughts/attempts committed by the ill relative". These burdens had resulted in poor mental and physical health among these carers. Coyne et al. (1987) pointed out that carers' burdens were positively associated with measures of psychological distress while Song, Biegel, and Milligan (1997) revealed that subjective burdens were positively correlated to depressive symptomatology in carers.

The Alliance for Advocating Mental Health Policies had interviewed 113 relatives of mental patients in

Hong Kong. The result shows that almost 70% of the respondents were depressed and 33.3% reported serious symptoms of depression that required immediate help (The Alliance for Advocating Mental Health Policies, 2007). The study conducted by Wong et al. (2012) also found that the quality of life (QOL) of Hong Kong carers was significantly poorer than that of the general public in Hong Kong, mainland China and Taiwan, as well as their counterparts in mainland China.

Positive Experience of Caregiving

More and more studies have supported that caregiving is not only associated with negative consequences like poor QOL, but also produces positive impacts on the carers, such as personal gains, satisfaction, rewards, positive caregiving experience and on carer's self-esteem (Kate, Gover, Kulhara & Nehra, 2012).

A study conducted by Hsiao and Van (2009) found that family carers with a more positive interpretation of family caregiving reported a lower level of family carer burdens. In another study, Pickett, Cook, Cohler and Solomon (1997) reported that parents' positive appraisal of their relationships with their mentally ill adult children were significantly related to a decreased level of carer burdens.

Unfortunately, there is a dearth of study investigating positive aspects of caregiving among carers of relatives with mental illness in Hong Kong. There is a need to examine the factors and sources of caregiving gains for Hong Kong carers in order to reduce their burdens and improve their QOL. The current large scale survey aimed at exploring carers' positive and negative caregiving experience.

Objectives

1. To investigate whether there is any change in QOL between the current sample (2014) and the sample studied in 2010 (Wong et al., 2012)
2. To investigate the effect of positive aspects of caregiving on the relationship between QOL and carer's burdens among carers of their relatives with mental illness
3. To investigate the source of carer's burdens
4. To investigate the extent to which the needs of carers in providing care to their relatives with mental illness are met and/or unmet

Methods

Participants

Informal carers of people with mental illness were recruited. Other inclusion criteria were 18 years old or above and be able to read and understand Chinese words.

Procedure

The participants of the survey were recruited by the staff of Baptist Oi Kwan Social Services. A convenience sampling method was used. A consent form and a set of self-reported questionnaires were disseminated to the eligible participants. The duration of data collection lasted for about 4 months.

Instruments

Experience of Caregiving Inventory (ECI). The ECI was developed by Szmukler et al. (1996). The original ECI is a 66-item self-report questionnaire which assesses carers' perceptions of their experience of caregiving. The measure is comprised of 10 subscales, 8 of them are negative aspects of caregiving and 2 are positive. This study adopted the 2 positive subscales (Positive personal experiences, and Good aspects of relationship) and 2 negative subscales (Stigma and Problems with services) with total 27 items with the aim of assessing positive experience of caregiving. The scale has been translated to Chinese and validated by Lau and Pang (2007) in which the Cronbach alpha of the subscales ranged from 0.49 to 0.85.

Perceived Stress Scale (PSS). The scale was developed by the PI (Wong, 2000). It aims at measuring carer's perceptions of the intensity of stress associated with difficulties encountered in the care of persons with mental illness. Each item is rated on a four point scale, which denotes the degrees of

intensity of stress experienced by carers from “very substantial” to “no stress”. Questions 1, 2, 7-12 belong to “Stress related to difficulty in handling negative symptoms of people with mental illness”. Questions 3-6 belong to “Stress related to difficulty in handling positive symptoms of people with mental illness”. Questions 13-16 belong to “Social costs associated with constant care of people with mental illness”.

Family information and support needs. This measure was adapted and modified by the authors of a survey study (Drapalski et al., 2008). It aims at assessing four areas of information and support needs of a family. They include need for information about (1) the relative’s mental health (Questions 1-5), (2) negotiating for services (Questions 6-9) and (3) community resources (Questions 10-12), as well as (4) need for skills for assisting a relative with mental illness (Questions 13-16). Four possible conditions were identified and then collapsed into two categories that reflect unmet need (current need because information was never received or they did not receive enough information) and receipt of information (any prior receipt of information). Number of unmet needs was tallied by the four areas of family information and support described above and in an overall score (Possible number of total needs range from 0 to 16).

World Health Organization Quality of Life Scale - Brief (WHOQoL - BREF). The Hong Kong version of the WHOQoL – BREF was used. It consists of 26 items assessing QOL in four domains including (1) Physical Health, (2) Psychological, (3) Social Relationships, and (4) Environment, and 2 items measuring the overall QOL and general health. In addition, Question 1 assesses the overall level of QOL and Question 2 assesses the overall level of health. Each item is rated on a five-point Likert scale, ranging from 1 (Not at all / Very dissatisfied / Very poor) to 5 (An extreme amount / Very satisfied / Very good).

The higher the score, the better the QOL reported. The Hong Kong version of the WHOQoL-BREF has been validated and found to be especially useful in assessing long-term outcomes (Leung, Wong, Tay, Chu, & Ng, 2005).

Statistics

The statistical analysis was conducted using the Statistical Package for Social Science version 21.0 (SPSS v21). Statistical significance was set at $p < 0.05$.

Results

Basic demographic information

A total of 331 carers were included in analysis. About 24.5% of carers were male and 72.8% of carers were female (missing data=2.7%). The mean age of carers was 55.3 years old (Standard deviation, SD=12.8). About 73.3% of carers were living with the patients with mental illness. About 55.6% of carers were parent, 12.4% were spouse, 14.5% were sibling, and 12.7% were son/daughter, of the patient with mental illness. The remaining 1.8% had other relationship with the patient with mental illness, such as friend, aunt, great grandchild and sister-in-law (missing data=2.7%).

Among the 331 patients who were taking care of by the carers included in this study, 46.8% of them were male and 50.5% were female (missing data=2.7%). The mean age of patients was 37.4 years old (SD=15.5). About 38.7% of patients were diagnosed with schizophrenia, 26.9% were depression, 12.7% were anxiety disorder, 11.5% were obsessive-compulsive disorder, 10.3% were bipolar disorder, 9.1% were delusional disorder, 3.0% were dementia, 2.1% were personality disorder and 14.2% were other diagnoses such as Asperger, autism, panic disorder, attention deficit hyperactivity disorder, posttraumatic stress disorder. The mean duration of illness is 10.4 years (SD=9.4) and the mean number of years of care received from carers was 8.6 years (SD=8.2) (missing data=2.7%).

Questionnaire reliability

The reliability of each questionnaire was measured by Cronbach's alpha: ECI = 0.828, PSS = 0.955, WHOQoL-BREF = 0.887, Family information and support needs = 0.898. All demonstrated good reliability.

For Objective 1: To investigate whether there is any change in QOL between the current sample (2014) and the sample studied in 2010 (Wong et al., 2012)

Overall, The QOL of carers in 2014 were not significantly different from that of 2010 ($p > 0.05$), except that the QOL in environmental domain of carers in 2014 had small but significant improvement compared to that in 2010 ($t = 2.01$, $p < 0.05$) (Table 1). On the other hand, the QOL of general public were higher than that of carers in 2014.

	Maximum score	Carers of people with mental illness		General public from Leung et al. (2005) (mean)
		2014 mean (SD)	**2010** mean (SD)	
Overall QOL (Q.1)	5	3.13 (0.70)	3.08 (0.73)	3.45
Overall Health (Q.2)	5	3.17 (0.83)	3.12 (0.82)	3.29
Physical domain	20	13.69 (2.47)	13.37 (2.40)	15.41
Psychological domain	20	12.37 (2.54)	12.07 (2.55)	13.43
Social domain	20	12.88 (2.58)	12.87 (2.36)	13.83
Environmental domain	20	12.97 (2.28)	12.61 (2.10)	13.61

Table 1. Quality of life (QOL) (mean value)

For Objective 2: To investigate the effect of positive aspects of caregiving on the relationship between QOL and carer's burdens among carers of their relatives with mental illness

Positive experience of caregiving had a significant moderation effect on the negative relationship between QOL and carer's burdens [R = 0.503, R2 = 0.253, F(3, 273) = 30.771, p < .001]. The interaction term was significant (unstandardized regression coefficient = 1.954, t = 2.059, p < 0.05). As shown in Figure 1, when the perceived stress was high, carers with a higher level of positive experience of caregiving (the green line) had a higher QOL compared to carers with a lower level of positive experience of caregiving (the blue line). The red dotted circle highlights the discrepancy in QOL between the green and blue lines.

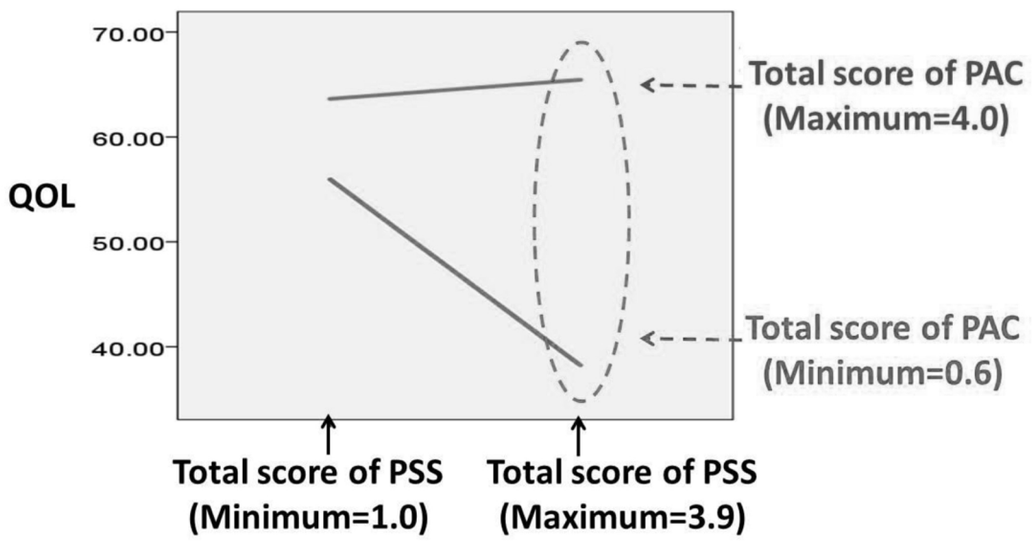

Figure 1. Moderation effect of positive experience of caregiving on the relationship between QOL and carer's burdens

For Objective 3: To investigate the source of carer's burdens

The mean levels of stress related to difficulty in handling positive symptoms (mean = 2.56, SD = 0.94) and negative symptoms of people with mental illness (mean = 2.34, SD = 0.9), and that related to social costs associated with constant care of people with mental illness (mean = 2.32, SD = 0.78) are similarly high. On the other hand, only less than around 15% of carers never felt any of the three types of stress mentioned above. Around 23-34% of carers occasionally felt the three types of stress and around 30-37% of carers often/always felt the three types of stress (Table 2).

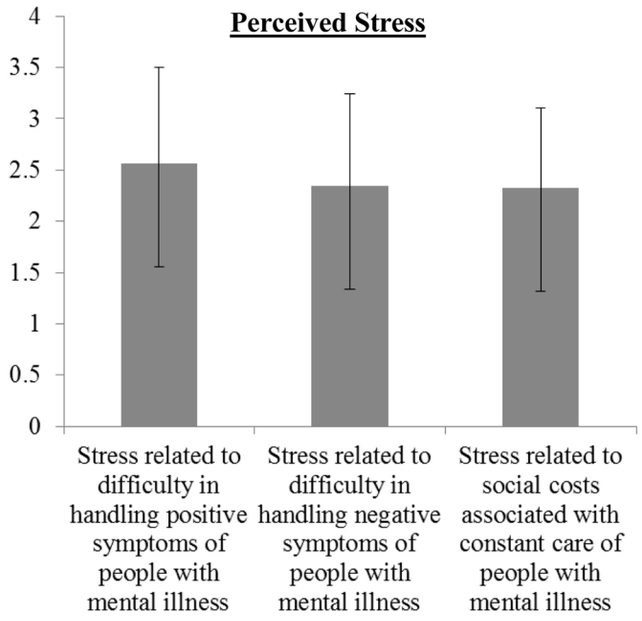

Figure 2. Perceived stress (mean value)

	Never (%)	Occasionally (%)	Often/Always (%)
Stress related to difficulty in handling positive symptoms of people with mental illness	14.6	28.3	30.3
Stress related to difficulty in handling negative symptoms of people with mental illness	13.6	23.2	37.0
Stress related to social costs associated with constant care of people with mental illness	14.5	34.1	30.7

Table 2. Perceived stress (%) (Note: The % of 'Not Applicable' was not shown)

For Objective 4: To investigate the extent to which the needs of carers in providing care to their relatives with mental illness are met and/or unmet

Figure 3 shows the percentages of unmet needs of carers. The most unmet need for information of carers related to a long-term rehabilitation plan for people with mental illness (75.8%), which is an item in the 'need for information about community resources'. While the least unmet need for information of carers was about how to obtain a diagnosis from psychiatric doctor (48.8%), which is an item in the 'need for information about negotiating for services'

The most and least unmet 'need for skills for assisting a relative with mental illness'of carers were about the procedures of handling crisis (68.1%) and how to persuade family member who has mental illness to take medication on time (48.8%) respectively.

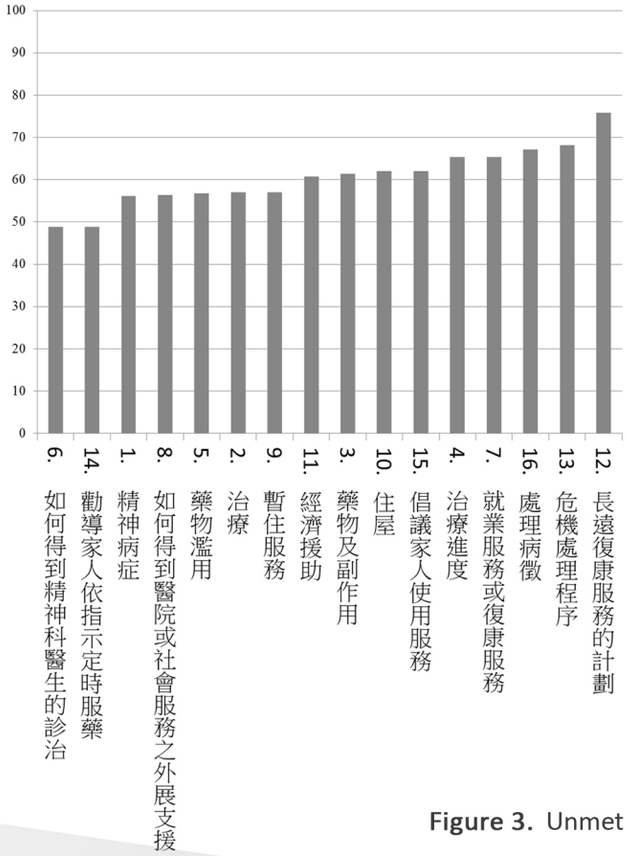

Figure 3. Unmet needs (%)

Discussions

This survey study investigated four questions relating to the perceived stress, QOL, positive experience of caregiving and unmet needs of information and skills in carers of people with mental illness.

First, the QOL in the environmental domain of carers in 2014 improved compared to that in 2010. The environmental domain includes the physical safety and security of living environment, quality of physical environment (e.g. pollution, noise, climate and landscape), financial resources, opportunities for acquiring new information and participating in recreational/leisure activities, and accessibilities of medical service and transportation. The improvement in QOL in the environmental domain may be related to the implementation of Integrated Community Centre for Mental Wellness (ICCMW) in all major districts in Hong Kong since October 2010. Some scopes of the services provided by ICCMW coincide with some factors determining the environmental domain of QOL, such as the networking services which include social and recreational activities, public education programs on mental health and outreaching occupational therapy training services provided to people with mental illness and their carers. In particular, the public education programs and outreaching services may indirectly enhance the opportunities for acquiring new information and increase the accessibility of medical services by easing transportation-related issue respectively.

Second, we found that positive experience of caregiving can moderate the negative relationship between QOL and carer's burden. In other words, a high level of positive experience of caregiving is important in enhancing QOL, especially when the caregiving burden is enormous. This finding is the first of its kind in Hong Kong. It corroborates earlier findings on the effects of experience of caregiving, coping style, and resilience on emotional and physical health (Szmukler et al., 1996; Fernández-Lansac, Crespo López, Cáceres, & Rodríguez-Poyo, 2012), which has a close and positive relationship with QOL (Chou et al., 2014).

Also, another study found that optimistic carers under high levels of stress had lower depression symptoms compared to their non-optimistic counterparts (Marquez-Gonzalez, Losada Baltar, Peñacoba Puente, & Romero-Moreno, 2009), while depression is negatively correlated with QOL (Price et al., 2002). It is possible that positive experience of caregiving includes adaptive coping strategies, which could counteract negative emotions and thereby uplift QOL. This finding carries important implication for the design of intervention programs for carers to cope with caregiving stress.

For instance, Baptist Oi Kwan has recently been providing various courses addressing the specific kinds of mental illness such as OCD (Obsessive Compulsive Disorder), BAD (Bipolar Affective Disorder), early psychosis and depression from the carers' perspectives. Those courses equipp the carers with knowledge of illness management and also enable better communication between the carers and the mentally ill relatives. Furthermore, the concepts of positive psychology; cognitive therapy and mutual support group have been run to enhance the carers' emotional management and to bring out the internal resource of carers, which include elements of gratitude, love, and compassion, while also incorporate recovery model and expressive arts. These activities provide a platform for carers to express and manage their own emotions and stress. In the future, we suggest conducting research to study the effectiveness of these psycho-educational and therapeutic groups, particularly those related to the impact of generating and consolidating carers' positive experience and hope. Eventually, we would like to develop a protocol for supporting carers in the long run.

Third, our carers face similarly high levels of stress related to difficulty in handling positive and negative symptoms of people with mental illness and social costs associated with caregiving. While most of our carers (73.3%) were living with their family members who have mental illness, it is possible that the high levels of

stress our carers face may be linked with the space of living place and their living habits. In fact, during our focus group interview with seven female carers who participated in our survey study, most of them admit that long duration of contact with their family members with mental illness at home give them a great deal of stressful feeling. Even so, they usually tend to stay with their family members with mental illness at home all day long due to the high dependence of their family members or their own concern about leaving their family members at home alone. Hence, most of them do not own much personal space and time to develop their own interests. Here, an important message is that, carers need to learn to take good care of themselves before they could take care of their family members with mental illness. Furthermore, the high level of stress related to social costs associated with caregiving also reflects that carers may need financial support to reduce some aspects of perceived stress of caregiving.

Fourth, the most unmet need of our carers fall onto the need of a long-term rehabilitation plan for their family members with mental illness. In particular, due to age and health-related concerns, carers who are older than their ill relatives (e.g. parents of ill children) desperately need to know how to develop a long-term plan for their young and ill relatives, as reflected in the focus group interview. The long-term plan goes beyond temporary home-stay or short-term home-skill training provided by occupational therapists. Ideally, the long-term plan should involve a designated person to commit to provide long-term care and supervision to the patient (i.e., to take over the role of the old carers when they will become unable to take care of their ill relatives). It is very important because patients are usually unmotivated to take care of themselves if they are not under close supervision, even if they have learnt different kinds of home skills.

Fifth, the carers in this study found unemployment issues of their children are one of their main concerns,

particularly those in their youth. This is understandable because the transition from adolescence to adulthood is challenging. It is a time when these young people have to make complex decisions about schooling, work, finance, and personal relationship. For youth with mental health difficulties, these challenges are even greater.

Some carers expressed that most of their young relatives have limited choices in employment. Despite the fact that they may not understand the value of work in recovery, carers felt that their young relatives need connections to a full range of youth employment programs. For instance, they need opportunities to gain and practice their work skills in workplace setting; connections to successfully employed peers and role models; knowledge of effective methods of stress management to cope with work stress; knowledge of and access to a full range workplace support and accommodations; and connections as early as possible to programs and service for career exploration provided in non-stigmatizing environment.

It is noted that the lack of long-term plan for the ill relatives may trigger a lot of stress in carers. They constantly worry that their ill relatives would not be able to take care of themselves, especially during relapse, which is a vulnerable period that may need urgent action in order to minimize any adverse consequences.

Overall, this study updated the current situation of carers of family members with mental illness in Hong Kong in terms of their perceived stress, QOL and unmet needs in caregiving. Furthermore, it provided some evidence on the improved QOL of carers in 2014 and the beneficial effect of positive experience in caregiving on improving QOL while counteracting high level of stress in caregiving. As reflected by the carers in the current survey, there is an urgent need to develop a long-term rehabilitation plan for people with mental illness.

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