

When I am Stressed Out - A Reflection on Caregivers' Concern

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I'm most honored not only because of the kind invitation to speak at this event but also for the opportunity to see many comrades and old friends who have dedicated most of their professional lives to helping people who are with a least fortunate situation in the society. Your commitment and your very loyal service throughout all these years has always been an encouragement and comfort to me and that I am not alone. Isn't it a similar kind of psychology that the caregivers need when we work with them?

This time I have chosen to do a different presentation by trying to bring some of my experience and research work in Hong Kong, China and Singapore and hope to give you special thoughts again on the topic of caregivers.

Burden of Care

I first worked with several groups of caregivers with children with intellectual disability (ID) in the 1980s and it is only until 2005 that I first started to research on the phenomenon of exceedingly long waiting lists for residential care for people with ID and, together with Dr. Hung, I started the research. It was not uncommon for a person with ID at that time to wait for more than ten years before a place for residential care was offered. Growing age and uncertainty and uncertain health trajectory of the caregivers coupled with the fear that the offer may come at a time when your life cannot afford to wait. It all

ends up in the vicious circle of fear and long wait listing. The survey findings with more than 300 caregivers revealed they never meant to shed the family responsibility to care and in fact they did not ask for many of the services. What they wanted was just an assurance of emergency placement when needed.

For three different groups of caregivers the need for emergency placement either short term or long term when needed is on top of the list (Table 1). On the side of the caregivers for people with mental illness qualitative interviews with both Hong Kong and Taiwan subjects showed situations that are equally perplexing. They think mental illness is a mystical knowledge beyond their understanding. They have no confidence in the recovery of a person with mental illness and have persistent blame on themselves. In fact these themes can be identified more easily among caregivers who reported unsatisfying encounters with medical staff and who found the service system not responsive to their needs. Again we see how individual psychology can be influenced and shaped by the environment which one interacts with.

In a more recent study with caregivers in Mainland China where support services are much needed but minimal in existence, 60% of the research subjects showed poor mental health, and can be predicted by anxiety level, affected stigma and concern of loss of face. This is where the culture comes in. Although caregivers' burden is generally reported all

Table 1
Three most wanted services by column percentages (incl. items > 10%)

	AG	WG	NG
Total items of service wanted	175	288	71
Items per person	1.37	1.81	1.82
#26 Guarantee that long-term emergency placement is available when needed	18.0%	33.1%	25.6%
#25 Guarantee that short-term emergency placement is available when needed		14.9%	
#14 Daily transport to day training centre		14.9%	
#16 Regular escort to day training centre	12.5%		
#5 High disability allowance	11.7%		10.3%
#33 Daily home help to help bath			11.5%
#34 Others			10.3%

AG, the admitted group; WG, the waiting-list group; NG, the non-application group.

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over the world, irrespective of their support level received, we suspect the manifestation of such burden may be culturally unique. For example, I think the sound of ID, apart from actual financial burden on the family and its less than average achievement in the future, one is actually losing someone to carry on the bloodline to achieve in the father's name and the loss of someone to provide for aging parents.

We carry on the analysis with some modelling and I am more certain now to establish several points. Some cultural values create threats and stress to caregivers causing poor mental health, however cultural values alone do not cause poor mental health. Affective stigma and anxiety level are mediators. They probably work to increase one's stress levels and lower one's coping competence.

You can see the cultural issue of face did not exert a direct impact on the GHQ, a mental health measure, as much as its direct impact via affective stigma and anxiety (Figure 1). Perhaps we need to add a note here that we examined only one particular kind of cultural value, that is loss of face, which we have suspected to be responsible for poor mental health but in fact there can be other cultural values that may render protective and resilient

function. We will need to identify it and work on it.

While long term residential care has been an old concern, respite care which is often of short term nature has received more contemporary attention. A recent survey involving more than 900 caregivers for persons with ID in Singapore, where family responsibility is emphasized and state support is only for the least abled and where there has been no formal respite care for people with ID, indicated the situations they may need respite care (Table 2). This wide range of reasons includes caregivers feeling unwell, exhausted, crisis situation, multiple dependence, change of domestic mates or workers to holiday needs. This is time when they need someone to take over part of their responsibility to care, at least for a short moment.

It was observed that these caregivers had a tendency to articulate their respite care needs in a more child-centric manner with little or no attention to their own support services. This is very often the case, they focus entirely on the disabled person and they talk about needs when they need help to provide better care but they never mention their own needs. Their life is submerged in care giving and they can only be a caregiver and they are no longer an independent, freely living individual.

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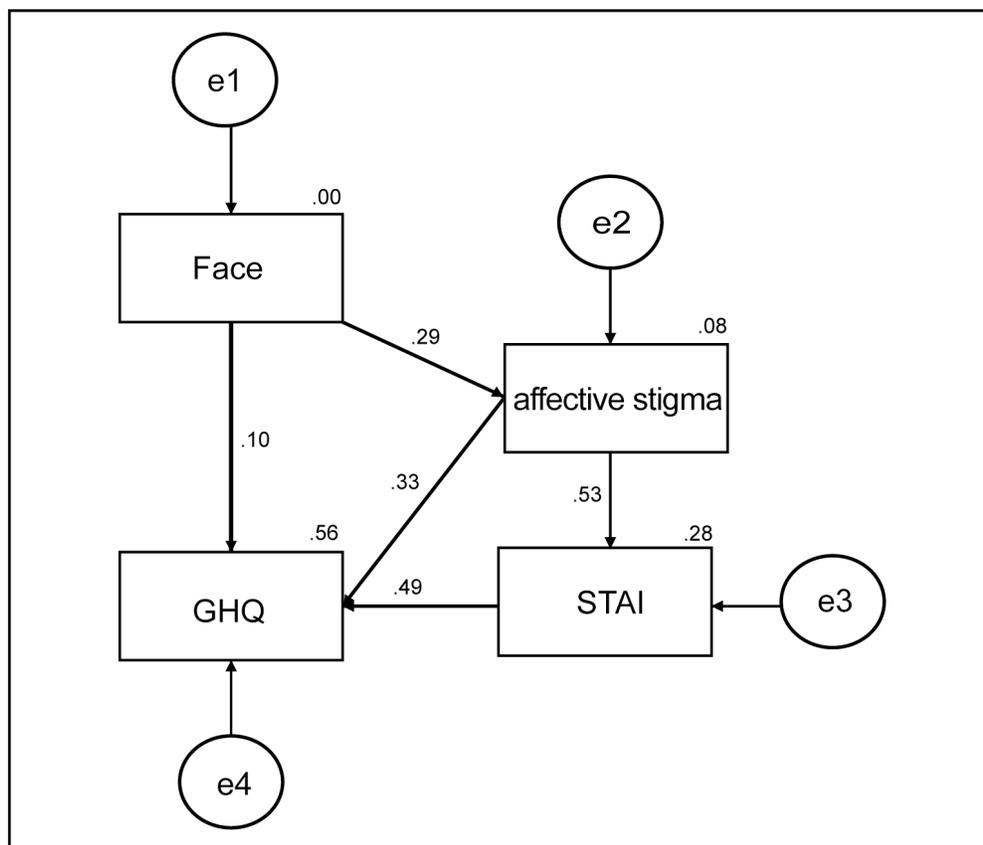


Figure 1: Structural model of the predictor (Face Concern) and mediators (affective stigma and STAI) of GHQ (Model 2)

Table 2
Situations Caregivers Need Respite Care (N=925)

Situations where Caregivers Need Respite Care	Need %
1. Feeling unwell physically	90%
2. Running out of energy / exhausted / burnt-out	84%
3. Crisis situation such as the death of a family member	83%
4. Care for another dependent who is ill	83%
5. Psychologically overwhelmed	83%
6. Short break / Breathing time	75%
7. Other situations	73%
8. Have overseas trip	67%
9. Change domestic worker	61%
10. Holiday	60%

We can observe from the list - top of the list is about child safety and then affordability, trained personnel, home safety, all these are about the nature of the service, the situation of the child (Table 3). Basically what they want, what they think is important is assurance that the child is in good hands with trained personnel or volunteers under a familiar environment and meaningfully engaged. But in fact we all know respite care may not be necessarily putting a disabled child in a place away from home, there can be many other forms of respite care. In other countries it can be friends or volunteers in the community, coming over to your house to help you with the

care giving not necessarily to take the disabled child away from home. But honestly this is something they doesn't exist in their concept that respite care can be in other forms.

Measured by different standards the wellbeing of these caregivers, more than 900 of them shows a proportion of poor mental health - ranging from 10% measured by K6 criteria, 36% by GHQ caseness and 55% by Caregivers Strain Index. 65% said that caregiving duty is actually quite heavy and 63% felt burdened. So we see the burden of care subjectively is a concern but never raised by themselves. It's only revealed by the survey.

Table 3
Important Factors in Respite Care Services (N=925)

Important to Caregivers (In Order of Importance)	Important
1. Child Safety	72%
2. Affordability	70%
3. Trained Personnel	59%
4. Home Security	39%
5. Support Services for Caregivers	39%
6. Convenience / Proximity	38%
7. Easy access to public transport	34%

- Assurance that child is in good hands, with trained personnel/volunteers, familiar with environment and meaningfully engaged
- Respite does not necessarily being away from child

We know there is a psychological stress in a caregiver with persons with a disability. Revealed by the Singapore 2010 National Health Survey there is only about 12.9% of ordinary citizens who show psychological distress. So if we compare the caregivers with ordinary people you find them three to five times more, depending on your criteria and the measurements taken.

The stress is largely determined by the number of child characteristics and caregiver characteristics including the severity of the disability. When there is a young child, usually

a young child would involve more stress on the caregivers than an older child, whether the child at the same time has a chronic illness and whether the child has ASD or ID. Then on the side of the caregiver whether they are well educated or not. Interestingly enough a better education standard did not actually lower your stress. It increased your stress because the more educated you are then you try to think hard for your child, you become more concerned, you become more involved, you think of every way that you can search for information and do whatever you can to bring the best for your child.

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Of course households with more incomes will mean more resources, you can hire support, you can hire maids to help out, you can go out and pay for social expenses while a low income family with a disabled child will keep them mostly at home. That's why in Singapore you won't see many disabled children on the streets outside. Finally if the caregiver is growing old with chronic illness I'm sorry to say that the caregivers can't even take care of themselves not to say the disabled child.

Very often we rely on the family to take care. This is something we feel very privileged as a family member even though many times we think that it's a burden but at the end of the day what keeps them moving, what keeps them working so hard, contributing without blame and doing it ceaselessly, for the improvement, for the life of the disabled child. It's actually just about the bonding, the emotional tie which we in Chinese regard as something inherent that comes about without much effort but we treasure it as a kind of binding force. It's OK to ask caregivers to take care as long as they are well and alive and kicking but in bad times we can't assume that caregivers have the courage, have the power and energy to do that. If you put all those responsibilities on the family without supporting them, I tell you that this explains why from time to time there are tragedies in the community when they are all stressed out, with no way out. Of course there's a way out, but what they perceive is when there's no way out, some tragedies like killing the child and killing themselves together.

So you see there are always pros and cons while we focus on family responsibility and in Singapore it's very good that it's a 'many helping hand' approach. On the good side many people are involved and the family would not feel alone.

Men Mental Health

The second issue I would like to bring up is about the cultural issues especially men in

the Asian context. This morning I remember Professor Sally Chan and also some of the previous speakers mentioned the situation may be very different under the different cultural context. In fact being a man - he looks very shining and bright - you are the head of the family, you walk out and find many, many friends in the community but essentially men are not just a tiger, men are a beater.

First you have to fit the master in the family - you are required to make decisions and then you are the first one to handle threats, dangers and challenges but the trouble is you are not trained in a very proper way. Sometimes when we work in kindergarten we asked to stop crying because you are a boy so we are not good in emotional expression. We cannot blame ourselves, we have to blame our teachers. Then men are always portrayed as a cool headed executive who always makes the right and objective decision and cannot be emotional.

But in fact men in modern society are under much stress, we need someone like women, like any other people, we need someone to listen to us. And we need a place where we are no longer tasked with the role and duties. The trouble is in a Chinese family whenever you appear you have to shoulder some responsibilities. Then we need a place to show that you are not as strong as other people think, and a place where you can talk freely without worry of rejection or affecting other people.

So we ran this men's group. In the first session somebody said 'what troubles you?', 'what trouble you are in?', 'what trouble you'. This one said 'sorry, sorry, Dr. Chiu, in fact when I took the transport, I thought, so good suddenly if I had a traffic accident then I do not need to feel troubled - I died, I really thought so'. It's not very fluent because it's in broken language and you can see in red the Chinese form.

So in the first session a gentleman, who is a caregiver of someone who is mentally ill, said to other men actually it might be better for me to die - I don't want to feel cuddled. The other one said 'it's not that I don't like to go home. I like it very, very much, but I'm so helpless to have conflict at home'. So you see the caregiver faces the disputes and conflicts at home. That makes him feel helpless, partly, I think, because men's cultural expectation is almighty, able to handle conflicts and able to settle everything at home but when somebody is there to dispute with you then you will easily feel helpless.

And another one - the son blame him for taking him to a mental hospital. After a long paragraph of airing the trouble and then finally the question - 'Is it me who has the problem?' So from being the target for blame, gradually the person doubted himself. So you see men under stress, men are not that strong and external problems can be turned inward.

For CBT, for any other forms of psychotherapy to take effect, usually we use externalization, you have to handle that right and to increase a person's self efficacy before you can really carry out the task of CBT. But emerged in troubles, in those feelings, and then you begin to doubt your own competence.

Finally here you see they describe the interaction between the ill person and the caregiver. It's like what? It's like two beasts in the same cage. What does it mean? It's like two women in a house - sorry I have no intention of to offend you ladies - there must be a fight - kill - someone wins and someone dies. So you see they are describing such a helpless situation - like caging two beasts in the same cage.

Every dream is shattered and then this man is so genuine, he said 'I cried'. I find it hard to translate it, in the Chinese way it means 'I cried and dying and dying' - it means

I cried so much. And then 'I lost everything, everything's gone'. The real practice is not that everything has gone but the perception and feeling is.

And then we talk about dreams. We can have many simple dreams. While we provide opportunity to talk about it, interestingly it's not something big, it's not about making big money, making a happy life, a successful life. It's about building some cartoon models, building a rail model, or doing photography, listening to music, or even to fold some paper works. These are the dreams but they didn't talk about it for a long, long time ever since their beloved one was ill.

What we learn is depression is common, no need to pathologise it, yet do not leave it unattended or untreated. Stigma operates in cultural contexts, we need to go into, we need to walk into the lives, the feeling and perception of those people before we can help them. There are structural issues that make people feel helpless. I always believe systems shape individual behaviors - sometimes systems and procedures may make people feel helpless. I can have this kind of feeling both in Hong Kong and Singapore when I find the repairing to come to fix the gas tap and gas stove, they never come on time. Just a tiny bit of thing will really stir me up because I'm a man.

Involving Caregivers

So mental illness affects both the person and caregivers and recovery means not just the person's recovery, it's a dual track of recovery for both the patient and the caregivers. We are in the system, we are not outside (Figure 2).

And finally this page - thank you for bringing us in. Where's the way out - how are we going to tackle all this? So I would say caregivers - one major problem I find is not about practical problems of getting along or relationship communication or knowledge

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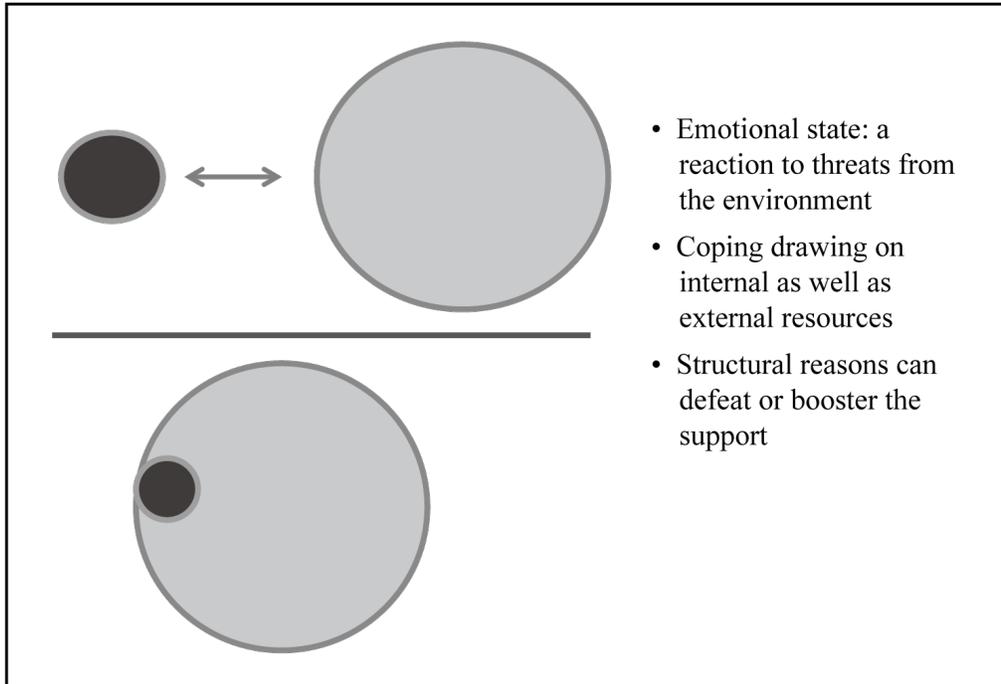


Figure 2: Person v.s. Environment

about psychiatric illnesses. One key issue is that when mental illness or disability happens in a family then there follows a relational poverty. When you look into the relationship it's no longer a normal one and then we have to work very hard to restore this relationship.

While we talk about empowerment, talk about resilience, there are many good things in cultural elements, in cultural values but there are prerequisites before we can take on these cultural resources. We need to understand how culture works and we need to develop culturally sensitive practice in order to engage and walk into the lives of these people. We all want them to feel that they are not alone. We all start to tell them you are not alone but the ultimate destination should be that they come to the realization that 'I know that I am not alone'. Then from the very disadvantaged position of having problems here and there from that position to become someone who can

contribute something and to find the meaning of life even though life is like that.

So this realization needs much help and companionship on the journey. Depression is not an enemy to eliminate and it is a friend to put up with. Why I find in many of my studies and also other studies, intervention helps bring down depression but it never goes away, it's decreased significantly but it never goes away. That means caregivers or people they care for have to carry this load from time to time throughout their lives. But my point is empowerment can take place even when somebody is feeling depressed. Of course the extent will not be to a very severe extent and finally we have to make the resources, treatment services available and affordable and make the procedure more human oriented and to facilitate better access, reduce structural barriers.

So I think I will draw this to an end and thank you very much.