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Lynne Cohen

Catherine Ferguson

Craig Harms

Julie Ann Pooley

Stuart Tomlinson

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Lynne Cohen¹, Catherine Ferguson¹, Craig Harms¹, Julie Ann
Pooley¹ and Stuart Tomlinson²

Family systems and mental health issues: A resilience approach

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¹ School of Psychology and Social Science

²CLAN WA

Edith Cowan University

270 Joondalup Drive

JOONDALUP

6027

Western Australia

Abstract

The CLAN WA indigo project enhances the resilience of family systems through providing support to individuals and families affected by someone else's mental illness through information sessions, workshops, one-to-one support and counselling. The aim of the project is to enhance resilience in the community of people who live with or support a family member with a diagnosed or undiagnosed mental illness. Participants were 15 carers (one male, 14 female). Semi structured interviews were transcribed and analysed using content analysis. Eight recurring themes emerged which indicated the challenges the carers faced and provided indications of the positive and negative personal and family factors that impacted on their lives. This program appears to have provided opportunities for enhanced resilience in its clients. There is still considerable work to do in supporting people who live with or support a family member in these circumstances. The findings demonstrate that individuals living with adversity can do more than just survive the process.

Keywords: resilience, family systems, carers, mental illness

Family systems and mental health issues: A resilience approach

People can face adversity during life and some encounter challenging situations which place them at risk of negative psychological, social and physical consequences.

Different people respond in different ways, some negatively to different situations (for example, substance abuse or violence), while others lead healthy and productive lives.

In this current research adversity refers to living with a person with mental illness (Lefley & Johnson, 1990). Recently researchers and practitioners have begun to examine the role of resilience in enhancing the capacity of an individual to adapt to adversity.

In 2008 CLAN WA, a community organization that works in areas of lower socio-economic status, partnered with the Lifespan Resilience Research Group at Edith Cowan University (ECU) to investigate aspects of the Indigo project. The focus of the Indigo project was on harnessing and developing the existing competencies and skills of an individual rather than focusing on the deficits. The Indigo project is a free service supporting friends, families and children who may be affected by the diagnosed or undiagnosed mental illness of a family member or close friend. Support is provided through information sessions, workshops and in home support services. Indigo is a national demonstration project developing and delivering new ways to help families build resilience (CLAN WA, 2008). This research focused on understanding aspects of resilience for those individuals living with a family member with a diagnosed or undiagnosed mental illness.

Defining Resilience

Defining resilience has been a challenge. Nevertheless, despite the vast range of definitions, to determine if someone is displaying a resilient profile two elements must co-occur: *adversity* (i.e., high-risk situation or threat) and *successful adaptation/*

competence (Luthar et al., 2000; Masten, 2001; Schilling, 2008). As maintained by Schilling (2008), adversity is evaluated according to the negative life circumstances as perceived by different individuals across different situations, such as death within the family. Adaptation, on the other hand, is defined as successful performance on age-developmental tasks. Other authors emphasise that resilience is characterised by *both* outcomes and processes. For example, Leipold and Greve (2009) describe resilience as a phenomenon which is defined by “the success (positive developmental outcomes) of the (coping) process involved (given the circumstance)” (p.41).

Rather than being guided by a specific philosophical orientation, a range of qualitative studies (Hegney, Buikstra, Baker, Rogers-Clark, Pearce, Ross, et al., 2007; Schilling, 2008; Ungar, Brown, Liebenberg, Othman, Kwong, Armstrong, et al., 2007) have investigated the concept of resilience, by asking participants how they would define the concept of resilience. One adult participant in Hegney et al.'s (2007) study on individual resilience in rural people in Queensland Australia mentioned: “I tend to think of resilience a bit like a rubber ball. If it's under pressure or something it can actually spring back to its size and shape and carry on without sustaining undue damage” (p.6). Interestingly this image of resilience as a ‘rubber ball’ and ‘bouncing back’ is an expression that has been used in other research and literature (see Smith, Dalen, Wiggins, Tooley, Christopher, & Bernard, 2008 who developed a Brief Resilience Scale assessing the ability to ‘bounce back’).

Finally, a new conceptualisation of resilience is proposed by Ungar (2008). He outlines an innovative ecologically focused definition:

In the context of exposure to significant adversity, whether psychological,

environmental, or both, resilience is both the capacity of individuals to navigate their way to health-sustaining resources, including opportunities to experience feelings of well-being, and a condition of the individual family, community and culture to provide these health resources and experiences in culturally meaningful ways (p.225).

Through the array of definitions, it is apparent that defining resilience has been and continues to be a challenge. This definition by Ungar (2008) underpinned the research described in this paper. However, the present research has focused on the protective factors that facilitate adaptation to living with a family member with a diagnosed or undiagnosed mental illness and the practicalities and challenges of navigating through the mental health system.

Resilience Models and Program Development: A Strengths Based Approach

From the literature it is evident that resilience does not only depend on individual attributes, but also on the protective structures that operate around the individual (i.e., the family, the community and the environment). A core principle by which resilience models or resilience program development operate is to *enhance resilience*. As Christiansen, Christiansen, and Howard (1997) outline, knowledge of the protective factors targeted to be enhanced needs to be reflected in program development. In terms of program development, Ahern et al. (2008) outline the importance of promoting positive behaviour, identifying risks, focusing on the family and on cultural and community resources in order to enhance resilience.

Adopting a systems approach program development needs to consider the individual, the family and the broader environment in order to successfully promote and enhance resilience in at-risk individuals (Bronfenbrenner, 1977). Enhancing or promoting resilience through program development and/or models runs counter to the traditional deficit-based models of assessment (Brinkman, Rabinowitz, Karuza, Coates, Cohn, & Kidder, 1982; Miller 2001). A resilience perspective expands on traditional models as the focus of assessment by placing greater emphasis on identifying the *strengths* and protective factors that surround the individual (Miller, 2001). As outlined by Simon, Murphy, and Smith (2005), the *resilience oriented approach* focuses on identifying and using the resources available to the individual. Furthermore, the interventions originate from the individual's strengths and resilience, it is solution focused and strength driven, and the outcome is to enhance and increase functioning.

Throughout the literature it is evident that resilience is a complex construct and there is still debate regarding its precise nature (i.e., is it an internal quality, an outcome, a process, an acquired skill?).

This research used a narrative approach to determine the protective factors and behaviours of individuals who have received support from CLAN WA to live with the adversity of having a family member who has been experiencing mental health problems. The goal for this framework is its application to inform health practice and planning for specific community groups through the application of ideas behind the concept of resilience.

Method

Participants

Participants were 15 adults who had actively engaged in services provided by a community organization in Perth, Western Australia through attendance at workshops and/or individual counseling or in home mentoring by the organisation's project officers. The interviewees were mostly aged 50 years or more; only one participant was male.

Procedure

Potential participants were contacted by the organisation's staff to determine their interest in participating in this study. They were provided with a brief letter describing the study and upon agreeing to participate, their name and telephone number was recorded to arrange a mutually convenient time and location for an interview.

In this exploratory research, semi structured interviews were conducted by experienced researchers to allow participants to tell their stories and outline their journey from the time they came into contact with the organisation. Information was sought as to the way(s) in which the organization provided the support and assistance to these people so that they could better cope living with a family member who may have been diagnosed with a mental illness. However, not all of these family members had been formally diagnosed with a mental illness by either a psychiatrist, psychologist or suitably qualified mental health professional.

Interviews allow much greater flexibility in asking questions rather than completion of questionnaires. The participant can seek clarification on any point and the interviewer can gain explanation on any incomplete or ambiguous answers to open ended questions. Such an approach is liable to afford the researcher data which has a "richness and holism, with strong potential for revealing complexitythick descriptions that are vivid, nested in real context, and have a ring of truth that has strong impact on

the reader" (Miles & Huberman, 1994, p. 10). There are many different types of interviews which include formal structured interviews; semi-structured interviews which is the informal conversational guide interview; the general interview guide approach; the standardised open ended approach (Patton, 1990). For the purposes of the present research, semi-structured interviews were considered the most appropriate form of interview. Therefore semi structured interviews were conducted using a funnelling technique whereby the interview began with broad and general questions becoming more focused and specific as the interview progressed (Oppenheim, 1992, p.111). Participants were encouraged to express thoughts, opinions and experiences that may be inhibited in the formal interview situation.

The interviews provided stories or narratives from which themes were produced to reflect the range of journeys experienced by the participants and the importance of the organisation's services and support to a group of people who hitherto had been ignored in terms of their own needs. With narratives there is the belief that telling stories is one of the important ways that individuals construct and express meaning (Mishler, 1991). The assumption is that everyone has within themselves a story and the way individuals make sense of their experiences is through shaping and telling the events in narrative form. In contrast to other interviewing techniques where participants are required to answer specific questions or confine their answers within a relevant framework, story telling offers a more natural mode of communicating. This does not mean that narratives have a place only in studies using unstructured interviews or where participants are encouraged to elaborate their responses (Mishler, 1991).

Narratives may be used as a direct source of gathering data similar to other qualitative methods. Individuals may be encouraged to relate stories when asked direct questions

as long as the interviewer does not interrupt the telling of the event or ask for clarification too often in the discourse (Cohler, 1982). By forming a collaborative partnership between the participant and the interviewer, this interview technique transfers control of the continuity and content of the interview to the participant. Within this methodological framework, interviewees provide a wealth of information within the context of their experience. Some interviews were undertaken at the organisation's offices. Where this was not feasible, home visits were arranged to maximize participation. Prior to commencement of the interview, participants were informed of their rights and the voluntary nature of the study, and signed an informed consent letter indicating their willingness to participate.

Method of Qualitative Analysis

The narrative form may be categorised in many ways, but this analysis relies primarily on a scheme derived from Glesne and Peshkin (1992). The data were content analysed separately by two peers, and the results were discussed, combined and where necessary, modified with the agreement of researchers.

Tape-recorded interviews were transcribed verbatim. A journal was kept in which memos and notes were recorded as this formed part of the audit trail (Drew, 1997).

While reading the transcript, significant statements were underlined. Common categories were then grouped together to represent a theme (Glesne & Peshkin, 1992).

These categories were conceptually similar regarding the experience. Figure 1 represents the procedure for analysis diagrammatically.

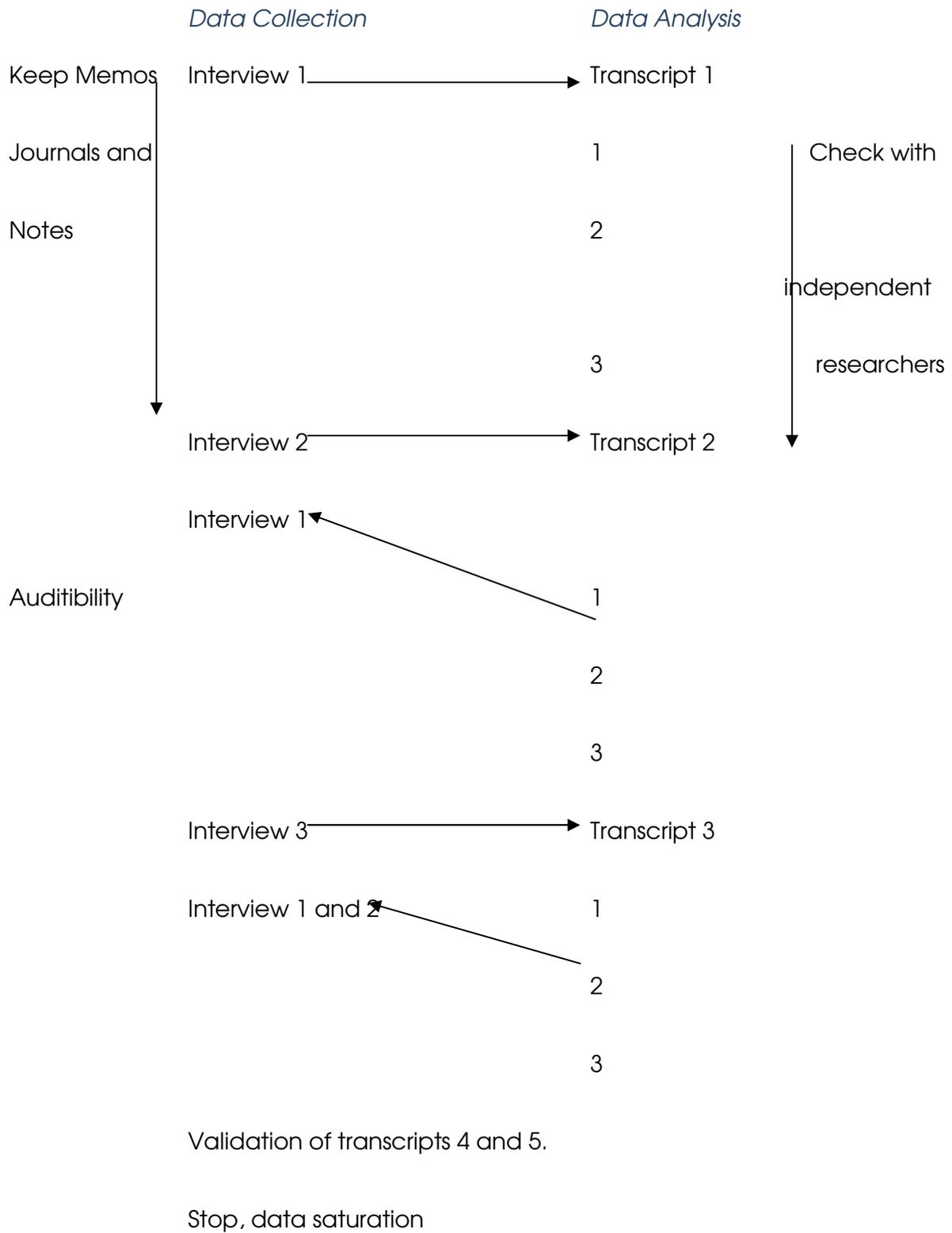


Figure 1 Representation of data analysis

Materials

The interview protocol used a funnelling technique whereby the interview began with broad and general questions becoming more focused and specific as the interview progressed (Oppenheim, 1992). In addition, the interviewer endeavoured to focus on the central components of resilience.

Results

An analysis of the stories that the participants told reveals several recurring themes which are detailed in Table 1 below. Many clients reported that they had been coping with their situation for many years. Times ranged from two years or so to over 25 years.

Table 1 here

Getting to CLAN WA

Participants came to CLAN WA and the Indigo Project through a variety of mechanisms. The Indigo Project has been marketed within the local communities to whom it is available through a variety of methods, such as newspaper advertisements for specific courses; posters placed in public places, such as libraries, community centres; posters and flyers mailed to specific professionals such as doctors, pharmacies; information has also been provided to local radio stations for inclusion in their community announcements. The most common method of finding out about CLAN WA cited by interviewees was the newspaper advertisements. However, in many cases the respondents did not say how they found out about CLAN WA and this would be a

useful mechanism for CLAN WA to implement to determine their most successful marketing strategy.

Accessing Help, including CLAN WA

In describing their journeys to CLAN WA and with CLAN WA nearly every participant talked about positive and negative experiences of accessing other services. Comments regarding CLAN WA services were all very positive

"I just felt as if I had somebody who was giving me a few answers, but not only that – but giving me the support and saying to me, but you know you have done the right thing; you are doing the right thing"

The following quote highlights the positive aspects of one participant's experiences with the mental health system. . .

"I have after many years have found a reliable sincere realistic psychiatrist"

(Speaking of Relationships Australia –referred from CLAN)

"I have been attending there for , in Gosnells for seeing a counsellor for about 10 months now and eventually encouraged my husband who hasn't been attending that long, but he found a counsellor there that he felt had a sense of being intimate and he's positive about continuing on with that"

However, in contrast, the following quotes illustrate the negative aspects of dealing with mental health professionals

"I had been saying for the 12 months prior to that that she had this problem and she was seeing a psychologist through DCP, who denied that she had the problem"

(speaking of mental health system)

"if you have an adult child who is in a desperate state – many of those regulations work against the extended family. And so the very network that could be of use provided they have understanding and information is cut off. And often then people are released out into the never never... or as we both know many self destruct.. or end up back out on the streets."

"Anyway he came to the hospital and he went and saw the doctor, but I went to see somebody as well, mental health or however it is there, and um, they said, there was nothing wrong with him and it was us. And for me to go back and get counselling, so I come back here and went for counselling, and the woman fell asleep on me."

and the pressures in the system

"and then, two days later she rang back, she said, oh we've got an influx of people we can't deal with it, and yours is being put on a back burner, can you go somewhere else basically."

The impact of living with a person who has a mental illness or problematic behaviour

People talked about a lack of knowledge and understanding both in themselves and in others . . .

"You don't understand it because I never understood mental illness, not until you are faced with it do you really understand it...and as she said in that workshop- people find it hard to understand because it's not a physical thing...it's all okay from the outside they just- they've got no idea, and they cannot comprehend it."

"And coming here to do that workshop, that really, really helped me to get – it gave me a better understanding of what he might be going through"

"And, so, um, depression we didn't know what depression was . . ."

"But I don't think... no.. nobody out there can understand the whole the whole thing it's too... it's too difficult to explain, I mean I can't even explain it to you because it's just so hard. And a lot of it's all sitting here and you say to yourself, yeah I need to talk, I need to get to get it out but... I don't know there's just so much questions why... what could I have done differently... Why does it, why did it always happen to be there and... that's hard. We're all given something to do... I keep on saying – maybe something will come out of it one day."

Family and Cultural Issues

Family issues indicated that family relationships are breaking down or at the very least strained. Respondents told of absent family members (often emotional rather than

physical absence and often in relation to male partners), less support within the family for the carer, little family cohesion, a lack of understanding of the situation.

...Do you get a lot of support from your husband? (Interviewer)

"Not really because when there's a trauma, he pulls himself away and goes and sits or sleeps or goes and lays down and you can't be handling..."

"And my efforts and my husband too he's got different ideas on how these things might be (takes a breath) handled, I think he still backs away and you know..."

"Um, he (father) just never has time for her and, um, he did come and live with her at one point but again, she just felt like she was used".

Many participants indicated a belief that there was no one else who would care for the individual with mental illness and that they had no other option but to personally take responsibility.

"Well you got no choice really. You got no choice really have you?!"

"Rightly or wrongly I'm battling on – you know... I sort of feel all this – I don't really have much choice."

"I was the only one to support her and I wasn't doing that good a job"

". . .you can't hold their hand all the time... but there are certain kids that need assistance – and I keep on thinking to myself, when am I going – if anything happened to me, if I got run over by a bus tomorrow... what is (son) going to do? Who is going to look after him? He'll be on the street."

Generational beliefs may also have impacted on these carers . . .

'From way back, I was in the war, you got no help- you just had to get on... get on with it... There was no counselling, if you were told- I mean I was evacuated- if you were told to go- you just have to do it, you know... No question!'

and mother's beliefs about their role add to family stress . . .

"I'm forever feeling guilty, this is my main problem, maybe I did say something a bit – that I overlooked something, should I try this approach, you know..."

Some participants reported feeling a lack of control over the situation;

"I'm saying it out loud now. That is enough! I can't take anymore of it. What can you do if you can't stop trouble coming to you. I honestly don't know how I'm carrying on."

and a there was a sense of acute and chronic stress;

"You just didn't know what, what phone call you're going to get next"

"Oh gosh. It just seems to be that constant state of worry as well".

Communication within the family

Linked to this theme of family and support was a strong theme about communication.

In many stories, there was a distinct lack of communication within the family and between the individual with mental illness and the carer.

"Umm, the way I deal with it, would be just keep out of his way. Keep, try and keep things running smoothly, let him do whatever he needed to do, and just keep my mouth shut."

"I didn't care --, yeah, because I couldn't, I had nobody to talk to, I daren't, wouldn't dare tell my sister or my mum and dad."

"he won't communicate, he's in denial and doesn't discuss anything... the behaviours are up and down... like a yo-yo. One minute he's OK, the next minute he's not and ummm then he's blaming you and you're the one that's at fault. He's never at fault – it's always YOU'RE the one that did this and you did this and the boss did this and somebody else did something else and... it's never, he doesn't take blame on"

One participant stated in terms of family communication between the family member with mental illness and his father . . .

"so they had no communication at all..."

On the other hand, another participant indicated open communication between the carer and the family member . . .

"...and then he told me, he admitted that he felt he was slipping and he needs to go on his medication. And he had a breakdown one night, in tears and everything"

and good communication between friends

"But I guess that helps then doesn't it when you've got someone that can sort of understand your situation"

Two respondents intimated that once they had become involved with CLAN WA and developed knowledge and skills, increased and better communications occurred within the family and between the person who was mentally ill and the carer. One participant suggested that initially, she like many others did not know what to do or say to her mentally ill son. Having attended the CLAN WA workshop she was much better informed and from there communication appeared to improve.

Coping strategies and evidence of resilience

Many of the carers indicated that they were still coping "day by day". For all participants, the CLAN WA interaction has been most positive, but many still find that the journey is long and arduous. There was a general feeling in the stories that the journey would never end, but has become easier because of the services and support provided by CLAN WA.

Several stories included coping strategies that included spirituality and other activities that took carers "away" from their responsibilities. Some used the term "escape".

"...And ah, I believe in spirit- I'm spiritually...I believe you are only given as much as you can handle...but I keep telling him up there: I've had enough!"

"And I managed to play my music, got my music on... and then a lot of it is... you have to live in a fantasy world. And that is where I go all of the time in my fantasy world"

"I might have a meditation and that's quite good."

"you know really some days I just get so ANGRY and so frustrated and not able to think clearly or want to do things... I really just want to disappear somewhere and never come back." (High pitch emotional)

"To combat that I used to obviously go in the garden. Keep, keep busy, do gardening."

Social Support

On a positive note, several respondents indicated social support from their church community and from friends. Although friends often did not understand what was happening for these carers.

"And people think- oh because he's you know depressed, it must be drug related... and it's not"

Some respondents also withdrew from their friends and communities. Sometimes this was because they were so busy caring for their family member; however in some cases they were concerned about how their friends would view the family.

Notions of Sacrifice

Several participants detailed changes to their lives. They gave up work to care for family members, gave up hobbies, and social events. They expressed a sense of putting life on 'hold' as they dealt with the needs of their family and family member with a mental illness.

"I've given all of that away, because I've got so much trauma in my life..."

"There are days when I wish I could still play tennis because that did help."

"I mean if I went down to Margaret River I would probably only get half way... and something would go wrong and I would have to come back..."

"And then, you stay home all weekend thinking that she'll might come, but she didn't come, so it's my fault"

Discussion

The stories presented in the interviews are the real lives of ordinary Australians. It is evident from these narratives that living with a family member with a diagnosed or undiagnosed mental illness, or who is demonstrating problem behavior has been very difficult for the participants in this research. Many participants have lived with this situation for a long time, up to 25 years. The interviews in this research were considerably longer than anticipated and it appears that the participants still needed to share their stories, suggesting that despite the work of CLAN WA there is still a considerable need to be addressed in this population.

Living with or supporting a family member with mental health issues brings with it physical and emotional health issues for the carers whose descriptions of their lives suggest that they are living with both chronic and acute stress. Several carers used the term "escape" which indicates a strong negative feeling about their life, and also suggests that they still have unresolved issues or "unfinished business" that require more intervention and support over a longer period of time. It appears that there are few services available to either the carer or the person who has a mental illness.

Additionally, many families are struggling, not only with the difficult behavior of their family member, but also with low incomes which places a financial burden on their already difficult position. Therefore CLAN WA are providing an important, essential, and

affordable service to an often ignored segment of the population. The comments of its clients suggest a positive effect on their lives, and for many of these people, a small change can have a large effect.

All the major elements of the literature on resilience are present in the stories of the participants – there is adversity, issues of support from others or lack thereof, and personal resourcefulness. As several participants indicated, friends often do not understand the situation of the families with an individual with mental health issues and this can result in reduced opportunities for social interactions and therefore social support. Participants also reported that there is still a considerable stigma attached to mental illness in the community.

The strengths based approach was used as the underlying framework to develop and implement a program to enhance the existing strengths within the individual. The people focused on in this research were the vulnerable carers and families of someone with mental health issues. This group has had little attention and it was apparent in the interviews that they found themselves in a particular situation over which they have little control and with which they had to deal. Strategies for enhancing program development were centred on the premise of working collaboratively and in partnership with the families within their own context to facilitate a person environment fit.

CLAN WA is making a difference to the lives of its clients. The interaction with this organisation has improved their quality of life in a number of important ways. The provision of the services provided by the project in general terms covered a variety of needs identified in the literature to increase resilience. These needs include, specific

knowledge about mental illness; skills across a variety of domains including what to say and or do and what not to say and or do; communication skills; stress management skills. Second, the feeling of social and community support including the interaction with others in a similar situation and the development of understanding of and between others was an important aspect of CLAN WA's involvement in the lives of their clients. Third, from many of the stories it was evident that these families are undertaking a journey which appears to be long and difficult and provides a range of challenges for these families, and for some the difficulties may never cease. However, the interaction with CLAN WA has provided them with the opportunity to develop their skills and competencies which helps them to improve and cope better with their situation. The interactions with CLAN WA facilitate this path so that clients may move from a chronic state of stress to an acute situation and back.

All participants expressed a sense of relief for the support provided by CLAN WA. The processes of workshop participation, interaction with others with similar experiences, and the in home support of CLAN WA workers appears to ease the strain on these carers. The resultant outcomes are that they are better equipped both with specific knowledge about mental illness and ways to approach the issues, and they are emotionally better prepared for the continuing journey that their family faces. Therefore the program has built capacity within the family facing adversity.

As the majority of the participants were female aged 50+ years a limitation of this research was that it is based on the perceptions and beliefs of older women. For those participants who were in an intimate relationship, the male partner was often "absent", emotionally, although not necessarily physically. This may indicate a variety of issues for

these men who avoid addressing the problem. It may suggest that these males are less resilient than their partners, and it may represent a generational and/or cultural aspect of life where the female adopts the role of the carer. Such generational issues may also be gleaned from the several participants who indicated that there was no one else who would undertake the role of the carer. It was their responsibility to do so and for most they did it willingly. But they also recognized that the role had been thrust upon them through their male partner's unwillingness to become involved. It was notable that not only did participants report lack of male partner involvement in the process of caring for the family member, but they also reported a perception that the male partners did not provide support for the carer. However, in these circumstances, women are often the vehicle or link to other family members who are less likely to seek help. Additionally, women often sacrifice their personal needs for the benefit of other family members and this was expressed in the interviews.

There is still much work that needs to be undertaken in the area of developing resilience across a different populations and in different contexts. Understanding what resilience means for other age groups, views of professionals about resilience, and the development of reliable and valid questionnaires are all important aspects of resilience research. From this research more intensive and relevant programs can be established.

The current research links to the existing knowledge on resilience and has provided some insight into the challenges that face families living with and or supporting a family member with a mental illness and how carers cope with these challenges. For resilience to be demonstrated, two aspects must be present. First, there should be an adverse circumstance or event and second, there should be evidence of successful

adaptation or competence (Luthar et al., 2000, Masten 2001, Schilling, 2008). The participants in this research provide strong evidence of their adverse circumstances as living with or supporting a family member with mental illness provides considerable challenges. The capacity of individual members within the family system is crucial to providing support to other family members.

A variety of research involving the concept of resilience has considered resilience as a personality trait, other theorists consider it a dynamic process which is contingent on context; others have integrated biomedical research; and still others have conceptualised resilience as a multidimensional construct. These differing views of resilience provide a challenge to researchers to accurately and comprehensively define resilience. In spite of the debates regarding resilience, what is important to note however is that individual attributes, the family and the social environment all seem to play a role in determining resilient outcomes and this is also evident from the emerging themes in this research. These themes demonstrated issues at the personal, family and society level confirming that in endeavours to enhance resilience, programs should consider all these aspects.

In conclusion the underlying framework that formed the basis for the development of the program focused on building resilience using a strengths approach. This model appears to be a successful way to engage and assist people deal with adversity such as caring for another with mental health problems or difficult behaviour.

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