Women mental health carers in the ACT

Preliminary Survey Findings

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ACKNOWLEDGEMENTS

Many thanks to all the community sector organisations that assisted in the dissemination of the research survey widely to women across the ACT. A very warm thanks to all the women who completed the survey and who encouraged other women to participate as well. It is your valuable experiences and insights that inform our mission for a health system that meets the needs of all women.

About the ACT Women and Mental Health Working Group

The ACT Women and Mental Health Working Group (WMHWG) has been meeting since August 2007, and was formed to provide a regular forum in which services providers and women living with mental health issues could work together on amtters impacting on women in order to provide improved outcomes for them, and to develop and maintain a full range of women friendly services.

About the author

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INTRODUCTION

Women are the predominant care-givers in contemporary Australian society[1]. They provide care to their children, their ageing parents, friends and extended family, and this can often negatively impact on their own health and wellbeing[2], family functioning[3], their education and employment opportunities[4] and future financial security.[5] For women caring for loved ones living with mental health issues, the challenges associated with balancing caring responsibilities and the rest of their lives are unique to those faced by other groups of carers. The nature of mental illness, for example, is known to be episodic with varying degrees of severity, and therefore the experiences of women providing care to individuals living with mental health issues is similarly variable.

In the ACT, there are 18,000 women carers[6]. Currently there is no available data which identifies the specific number of mental health carers at a national and/or state and territory level.

There is a burgeoning sum of literature that identifies the risks and difficulties associated with and specific to caring for individuals living with mental health issues, and due to the gendered nature of caring and its prevalence in our local community, it was considered appropriate that the ACT Women and Mental Health Working Group (ACT WMHWG) and the Women's Centre for Health Matters (WCHM), in consultation with Carers ACT, commission research into ACT women mental health carer needs and experiences.

This online publication, *Women mental health carers in the ACT: Preliminary Survey Results,* presents the preliminary findings of a survey, targeting women mental health carers in the ACT. The aim of the survey was to establish a quantitative and qualitative data set comprising of information related to women mental health carer health and wellbeing, their social and support networks and their involvement in their local community and decision making processes. This data will inform a more expansive report on ACT women mental health carers to be published in early 2011.

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[1] "Disability, Aging and Carers Australia: Summary of Findings ", ed. Australian Bureau of Statistics (Canberra: Australian Bureau of Statistics, 2004). 11

[2] "A Profile of Carers in Australia," ed. Australian Bureau of Statistics (Canberra: Australian Bureau of Statistics, 2008).39

[3] Ben Edwards et al., "The Nature and Impact of Caring for Family Members with a Disability in Australia," ed. Australian Institute of Family Studies (Canberra: 2008). 47

[4] Trish Hill et al., "Young Carers: Their Characteristics and Geographic Distribution - Report to the National Youth Affairs Research Scheme (Nyars)," ed. Employment and Workplace Relations Department of Education (Canberra: Report to the National Youth Affairs Research Scheme (NYARS), 2009). 77

[5] Julia Twigg, "Users, Carers and Care Agencies -- Conflict or Co-Operation?," *The Journal of the Royal Society for the Promotion of Health* 115, no. 4 (1995). 257

[6] "Disability, Aging and Carers Australia: Summary of Findings ". 11

METHODOLOGY

1.1. SURVEY DEVELOPMENT

The ACT WMHWG and WCHM, in close consultation with Carers ACT developed a 45-question survey for women mental health carers with the aim of collecting both quantitative and qualitative information relating to their health and wellbeing, the nature of their caring role and responsibilities, their social and support networks and their involvement in their local community.

1.2. SURVEY DISSEMINATION

Survey data was collected through online and hardcopy media. Respondents qualifying for the survey were women living or working the ACT or Queambeyan who self-identified as supporting or caring for a friend or family member who is experiencing mental illness.

Hard copy surveys were distributed through key organisations in order to target groups of women unlikely or unable to access the survey online. Surveys were delivered to organisations along with pre-paid, self-addressed envelopes so that they could be returned to WCHM at no cost. Organisations that received hardcopy surveys were the Citizens Advice Bureau, TANDEM, CYCLOPS, Carers ACT, the Women's Information and Referral Centre, the Women's Health Service and Woden Community Service.

The online survey was available via a link on the WCHM website and was distributed through email networks and personal contacts. A link to the survey was also available on the websites of the Mental Health Community Coalition ACT, the ACT Mental Health Consumer Network and Healthcare Consumers ACT, and via the ACT Health Intranet.

Information about the survey and the link were also published in the E-Bulletin's of Carers ACT, Youth Coalition ACT, the Transcultural Mental Health Network, the ACT Mental Health Consumer Network, Healthcare Consumers ACT and the ACT Office of Multicultural Affairs.

1.3. INTERPRETATION OF SURVEY RESULTS

Percentages presented from this survey are based on the total number of valid responses made to that particular question reported on. In most cases, results reflect respondents who expressed a view and for whom the questions were applicable. 'Not applicable/Unsure' answers have been included in the valid percent where this aids in the interpretation of results.

Responses from specific groups of women known to be disadvantaged in the ACT community (culturally and linguistically diverse (CALD) women, women with disabilities and women from low income households) were filtered out and compared to the overall sample. Any divergent responses have been noted in the survey findings.

SURVEY FINDINGS

2.1. DEMOGRAPHIC CHARACTERISTICS OF SURVEY RESPONDENTS

There were 80 survey responses, 79% (n=63) of which were complete. This sample represents 0.06% of he female population over 15 years in the ACT.[7]

Age: One percent (n=1) of survey respondents were 15-24 years; 30% (n=31) were 25-44 years; 53% (n=42) were 45-64 years; and 8% were 65 years or older.

Aboriginal or Torres Strait Islander (TSI): Of the survey respondents, 4% (n=3) identified as Aboriginal or Torres Strait Islander. There are 1256 Aboriginal or Torres Strait Islander women in the ACT who make up a total of 0.9% of the female population 15 years and older.[8]

Culturally and Linguistically Diverse (CALD): Of the survey respondents, 18% (n=14) reported that they are from culturally or linguistically diverse backgrounds. There are 41,553 women in the ACT who were born overseas who make up 31% of the female population 15 years and older.[9]

Women with Disabilities: Of the survey respondents, 37% (n=29) reported that they have a disability or long-term or chronic health condition. There are 5,373 women in the ACT who require assistance due to a disability, making up 4.0% of the female population 15 years and older.[10]

Work Status: Forty-nine percent (n=39) of respondents were working full-time; 28% (n=22) were working part-time or casual; 11% (n=9) were not currently in paid employment; and 6% (n=5) were retired.

Household Income: Twenty-eight percent (n=22) of respondents reported a total household income of $41,599 or less; 34% (n=27) reported a total household income between $41,600 and $88,399; 38% (n=30) reported a total household income $88,400 or more.

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[7] "Census of Population and Housing: Age by Sex – Australian Capital Territory" ,ed. Australian Bureau of Statistics (Canberra: Australian Bureau of Statistics, 2006)
[8] "Census of Population and Housing: Indigenous Status by Age by Sex – Australian Capital Territory", ed. Australian Bureau of Statistics (Canberra: Australian Bureau of Statistics, 2006)
[9] "Censure of Population and Housing: Country of Birth of Person by Age by Sex – Australian Capital Territory", ed. Australian Bureau of Statistics (Canberra: Australian Bureau of Statistics, 2006)
[10] "Census of Population and Housing: Core Activity Need for Assistance by Age by Sex – Australian Capital Territory", ed. Australian Bureau of Statistics (Canberra: Australian Bureau of Statistics, 2006)

Household Composition: 11 percent (n=9) of respondents reported living alone; 21% (n=17) reported living with a partner; 35% reported living with a partner and other family members; and 21% reported living with other family members.

2.2. HEALTH AND WELLBEING OF SURVEY RESPONDENTS

Unless otherwise specified, the survey findings were consistent across the different demographic groups.

2.2.1. Health and Wellbeing Status

Respondents were asked to self-assess their physical and mental health status on a 5 point Likert scale.

In relation to their physical health and wellbeing status, 14% (n=11) of respondents reported poor health and wellbeing status; 30% (n=23) reported fair health status; 42% (n=32) reported good health and wellbeing status; and 16% (n=13) reported very good or excellent health and wellbeing status.

None of the CALD respondents reported excellent physical health and wellbeing status. Fifty-five percent (n=6) of respondents who reported poor physical health and wellbeing status were from households with a total income (before tax) of <$41,999.

In relation to their mental health and wellbeing status, 11.5% (n=9) of respondents reported poor health status; 38.5% (n=30) reported fair health status; 33% (n=26) reported good health status; and 17% (n=13) reported very good or excellent health status.

None of the CALD respondents reported very good or excellent mental health and wellbeing status. Of those respondents who reported good, very good or excellent mental health and wellbeing status (n=45), only 8% (n=38) of respondents were from households whose total income (before tax) is <$41,999.

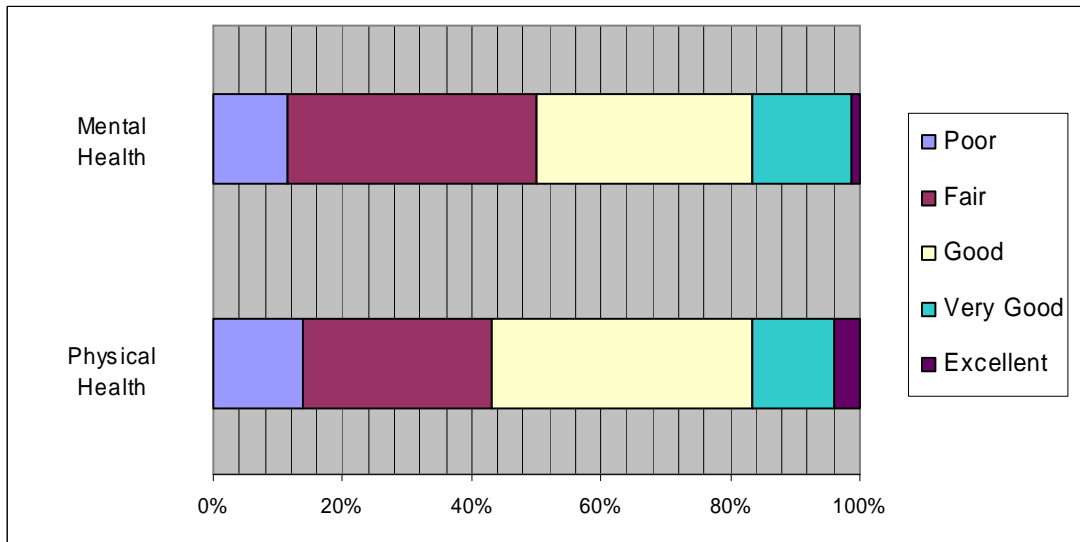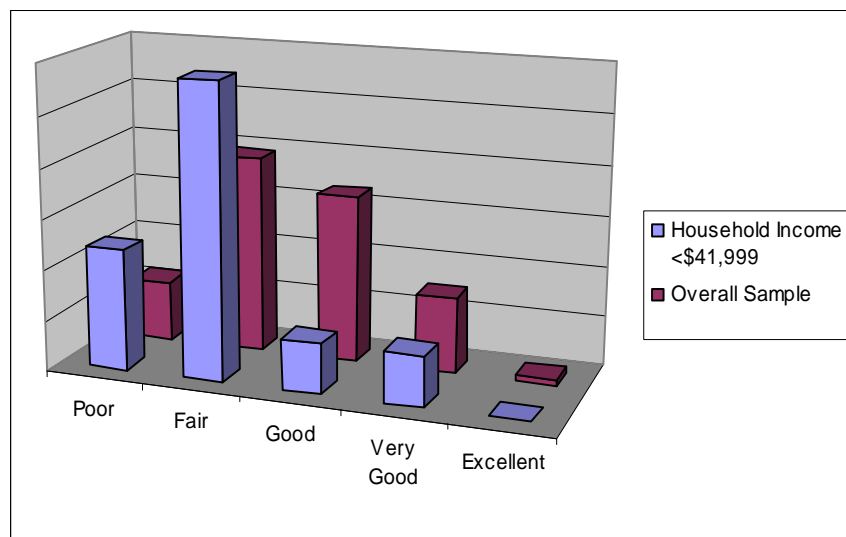Figure 1:   Self-reported levels of physical and mental health and wellbeing

Figure 2:   Self-reported levels of mental health and wellbeing of women from households whose total income is <$41,999 (before tax) as a percentage against the overall sample

2.2.2. Changes in health and wellbeing status as a result of caring responsibilities

Respondents were asked whether their mental health and wellbeing had changed since taking on caring responsibilities, and 68% (n=53) said yes.

When asked how their mental health and wellbeing changed since taking on caring responsibilities, many respondents identified physical health and wellbeing issues: 43% (n=21) of respondents talked about stress levels; 27% (n=13) mentioned fatigue or lack of energy; 14% (n=7) talked about their level of fitness and exercise; and 8% (n=4) indicated that there had been changes in their weight:

> *I am more stressed and have much less time to myself.*

> *I have no energy to socialise in my circle of friends… I am always tired as the stress of caring for this person is tiring.*

> *Stress levels raised, limited opportunities for life outside caring, poor sleep patterns, lack of exercise regimen, [and] increased family tensions.*

Of the 49 women who responded to this question, only two talked about positive changes to their mental health and wellbeing since taking on caring responsibilities. One respondent said:

> *I initially became very stressed, which was resulting in high blood pressure and anxiety. I took up a gym membership and personal trainer and have become very physically fit in order to continue my work.*

2.2.3. Responding to health and wellbeing needs

Respondents were asked whether they had enough time to respond to their own health and wellbeing needs. Seven percent (n=7) of respondents reported that they always had the time to respond to their own health and wellbeing needs; 59% reported only sometimes having the time that attend to their own health and wellbeing needs; 30% reported that they rarely had the time; and 1% (n=1) reported never having the time to respond to her own health and wellbeing needs.

2.2.4. Barriers to addressing health and wellbeing needs

Respondents were asked whether there were any factors that made it difficult for them to address their own health and wellbeing needs. Seventy-two percent (n=56) of respondents identified time; 63% (n=49) identified work commitments; 58% (n=45) identified caring responsibilities; 53% (n=41) identified cost. Moreover, approximately 1 in 5 respondents identified confidence as a factor in addressing their own health and wellbeing needs, and 1 in 3 respondents identified disability or chronic/serious health condition as a factor that makes it difficult to address their own health and wellbeing needs.

Forty-two percent (n=17) of respondents who identified cost as a barrier to addressing health and wellbeing needs (n=41), had also reported a total household income (before tax) of <$41,999.

2.2.5. Supporting women mental health carers to address health and wellbeing needs

Respondents were asked to provide qualitative feedback as to how women mental health carers could be better supported to address their health and wellbeing needs. Some comments from the survey included:

Men could take more responsibility for self-care and for supporting one another's mental health and wellbeing in positive ways (not only grog). They could also supply more support to women who do such caring.

I remember how caring my GP of 24 years was. He has now retired. He used to be so caring and bulk billed me even though the practice was largely a private paying practice (His first wife was bi-polar so this made him very understanding). I have no GP now who knows my history. I have no one to turn to - the GPs I've seen recently just aren't the same. Maybe we need to have some item numbers in the Medical Benefits Schedule - when we book to see a GP we ask for a carer's appt. This way we need not apologise for taking up their time. Maybe we need GPs who are carer support trained.

Free counselling and other helpful self help strategies such as massages, yoga, friendships/support.

Mentoring and support program - like having a coffee with a friend who understands/is in a similar situation.

Provide better support for the people we are caring for so that we don't have to run ourselves into the ground to fill in where there are gaps in support.

There is such a focus on caring for the mentally ill person, the family/affected people do not seem to matter much at all. I have had to initiate family conferences and have found that doctors/hospital staff in Sydney are much more open and communicative about the patient's condition and potential danger to the family, follow-up after discharge is also stronger.

2.3. THE CARING ROLE OF SURVEY RESPONDENTS

Unless otherwise specified, the survey findings were consistent across the different demographic groups.

2.3.1. Relationship to 'care recipient'

Respondents were asked what their relationship to the 'care recipient' is, whether they lived with the care recipient, how long they had been caring for this person and how many hours per week on average they spent fulfilling caring responsibilities.

Fourteen percent (n=10) reported caring for their partner; 73% (n=53) reported caring for another relative (i.e. father, son etc.); and 6% (n=4) reported caring for a friend.

Forty-three percent (n=31) of respondents reported living with the 'care recipient'; 31% (n=22) live less than 10 km away from the 'care recipient'; 11% (n=8) of respondents reported that the 'care recipient' was living in the broader ACT/Queanbeyan region; and 8% (n=6) reported that the 'care recipients' housing situation was either currently changing or frequently changing.

Six percent (n=4) of respondents said that they had been caring for the 'care recipient' for less than 1 year; 32% (n=23) reported caring for 1 to 5 years; 17% (n=12) reported caring for 5 to 10 years; and 45% (n=32) reported caring for more than 10 years.

Thirty-seven percent (n=26) of respondents spend less than 9 hours per week fulfilling caring responsibilities; 34% (n=24) spend between 10 and 19 hours per week; 13% (n=9) spend between 20 and 40 hours fulfilling caring responsibilities; and 16% (n=11) spend more than 40 hours per week fulfilling caring responsibilities.

CALD respondents reported living with the 'care recipient' at a higher rate than the overall sample at 64% (n=9). Forty-four percent (n=14) of respondents who reported caring for more than 10 years (n=32) and 73% (n=8) of respondents who spent more than 40 hours per week fulfilling caring responsibilities had also reported a total household income (before tax) of <$41,999.

2.3.2. Defining the caring role

Respondents were presented with a list of common tasks associated with caring and were asked to select those which applied to them.

Ninety-four percent (n=68) of respondents reported providing emotional support; 57% (n=41) undertake meal preparation and grocery shopping as part of their caring role; 51% (n=37) perform housework; and more than 40% (n>30) provide transport to and from appointments and pay for basic living expenses, medications and/or medical appointments.

2.3.3. Stigma and Discrimination

Respondents were asked whether they had experienced stigma and/or discrimination as a result of their role as mental health carer. 52% (n=35) reported that they had. Of those respondents who further elaborated on the nature of stigma and/or discrimination they had experienced, 31% (n=9) reported the loss of friendships and support networks, or not being able to confide in these people:

I have lost friends… when the first of my sons became ill, I was shunned by people in my workplace rather than showered with flowers and sympathy as happened to a colleague whose daughter had a car accident at the same time.

Lost a lot of friends who have not been able to understand my commitment to my child.

I maintained our privacy for a very long time. Even friends who knew our son's diagnosis would say, 'there doesn't seem to be anything wrong with him'. They would see him for 10 minutes while he made a coffee (he would then retreat to his room until the next coffee). When he took elicit [sic] drugs, people gossiped and showed no empathy. We choose what we say to people carefully – and it's only about 10% of the story.

Many people look at me as if I am going to give them a contagious disease.

Seventeen percent (n=5) of respondents talked about being viewed as responsible for the onset or exacerbation of mental illness in their loved one:

Family and general public do not understand mental illness and often choose to see it as bad behaviour or bad parenting skills.

People often think their condition is due to poor parenting and look at me as though I could have taught them better or been more of a disciplinarian.

My caring role and support has been described as 'mollycoddling'.

The stigma is with the person who has mental health [sic] – as her mother I feel judged.

I felt I was treated like a nagging mother, rather than [the] concerned and knoweldgeable [sic] parent that I am.

Only one respondent to this question provided a positive response:

By talking about it [stigma/discrimination} when the opportunity arises, I find there are plenty of people with some sort of mental illness, or are in a caring capacity for this. I think people on the whole are beginning to accept that there is a lot of mental illness in the world! I've never had a 'bad' reaction, whether from friends, aquaintances [sic] or complete strangers.

Survey respondents who reported a household income of <$41,999 (before tax) reported experiencing stigma and/or discrimination at a higher level than the overall sample (68%: n=13), as did respondents who reported having a disability or long-term/chronic health condition (70%: n=19).

2.4. THE SUPPORT NETWORKS OF SURVEY RESPONDENTS

Unless otherwise specified, the survey findings were consistent across the different demographic groups.

2.4.1. Personal support networks

Respondents were asked whether they had a network they could rely on for support: 66% (n=44) reported that they did; 35% (n=23) reported that they did not.

CALD responses were contrary to the overall sample with 62% (n=8) reporting no support network they could rely on and 39% (n=5) saying that they did have a support network they could rely on.

When asked to identify the people in their support networks, 70% (n=40) of survey respondents said friends; 56% (n=32) reported family; 28% (n=16) reported work colleagues; and 16% (n=9) reported other carers and members of a religious group.

Figure 3:   Composition of personal support networks
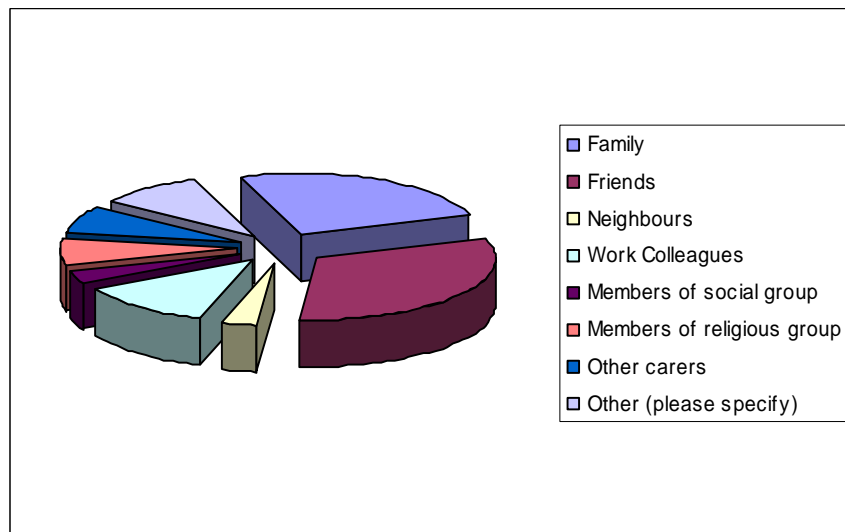
2.4.2. Responsiveness of support from personal support networks

Survey respondents were then asked to identify and rate which of these groups of people they were able to get support from in a crisis situation on a four-point Likert scale.

Partners

Fifty-two percent (n=34) of respondents said that they were either always or sometimes able to get support from their partner; 14% (n=9) reported rarely or never being able to support from their partner.

More then a third of respondents (n=23) reported not having a partner and respondents who reported a household income of <$41,999 were overrepresented in this category (52%: n=12).

Figure 4: Perceived levels of support from partners in a crisis situation
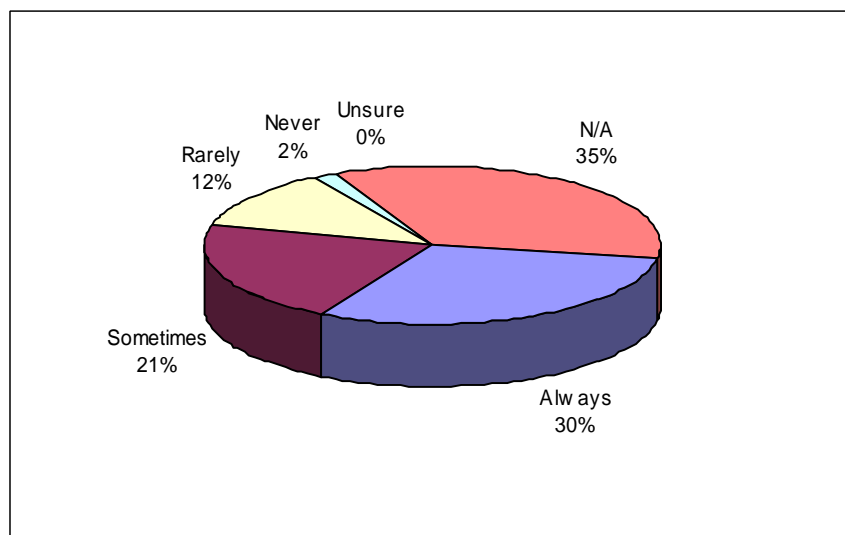
Family

Fifty-five percent (n=35) said that were always or sometimes able to get support from family; 37% (n=23) reported rarely or never being able to get support from family.

Of those respondents who reporter never being able to get support from family, 83% (n=5) were from households whose total income (before tax) was <$41,999.

Figure 5:   Perceived levels of support from family in a crisis situation
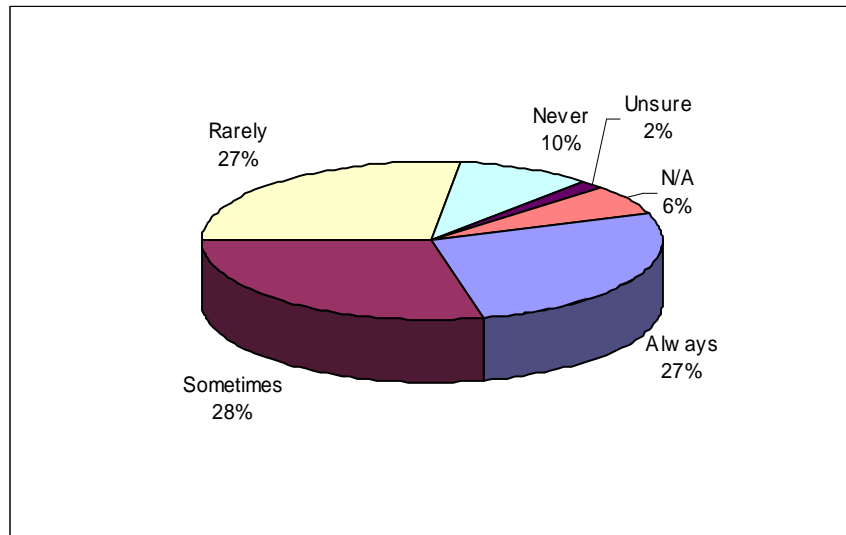
Friends

Sixty-eight percent (n=43) of respondents said that they were always or sometimes able to get support from friends; 24% (n=15) reported rarely or never being able to get support from friends.

Figure 6:   Perceived levels of support from friends in a crisis situation

Work colleagues
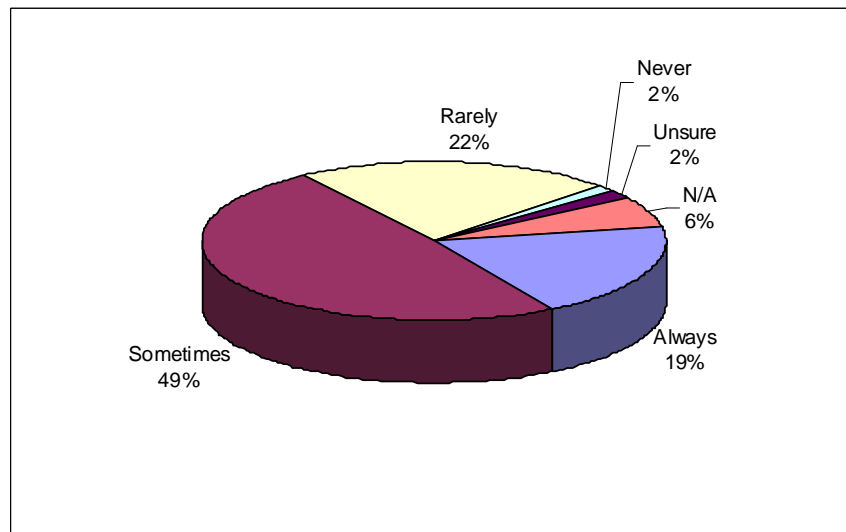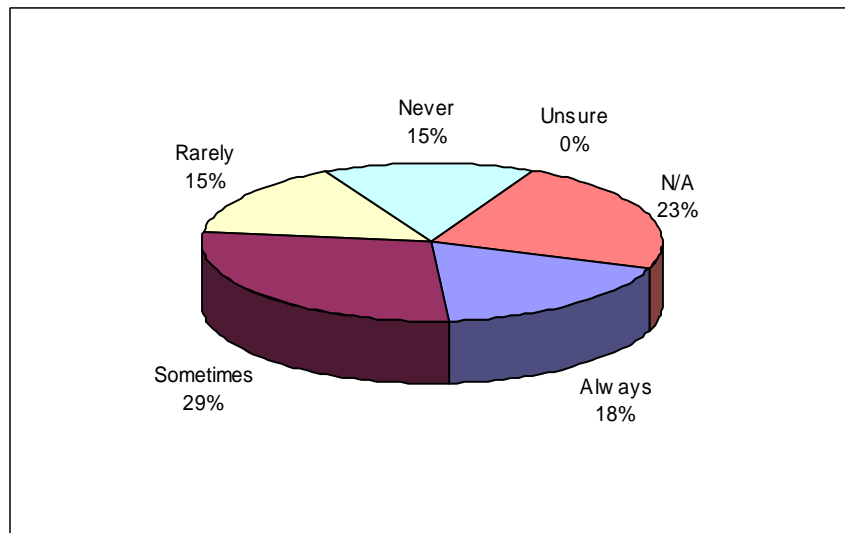
Forty-seven percent (n=28) were always or sometimes able to get support from work colleagues; 30% (n=18) were rarely or never able to get support from work colleagues.

Figure 7:   Perceived levels of support from work colleagues in a crisis   situation

2.4.3. Socialising preferences

When asked which groups of people they prefer to socialise with, 85% (n=57) of respondents indicated a preference for socialising with friends; 81% (n=54) with family; 28% (n=19) with work colleagues; 15% (n=10) with members of a religious group; 13% (n=8) with neighbours; and 7.5% (n=5) with other carers.

Respondents were asked to provide qualitative reasons as to why they preferred to socialise with these groups of people. Some responses from the survey included:

They are understanding and sympathetic; some I have known for many years.

Friends and colleagues away from the caring role. I don't want to be defined by my sister's illness.

…other carers are about the only ones who have a hope of understanding my situation.

…I like to spend time with intellectual groups to train and maintain my separate identity and interests.

…I socialise with friends when I can – so I can get away from it all. They understand my caring role and allow me to escape from it at social times…

My friends provide me space to be myself and to have fun where I don't have to always [be] nice or professional. My family allow me to pursue hobbies and to talk about things outside my caring role.

2.4.4. Responsiveness of professional support networks

Survey respondents were asked to identify and rate which professional supports they were able to draw on in the event of a crisis on the same four-point Likert scale.

Medical/mental health service providers

Fifty-eight percent (n=37) reported always or sometimes being able to get support from medical/mental health service providers; 36% (n=23) reported rarely or never being able to get support from them.

Figure 8:   Perceived levels of support from medical/mental health service providers
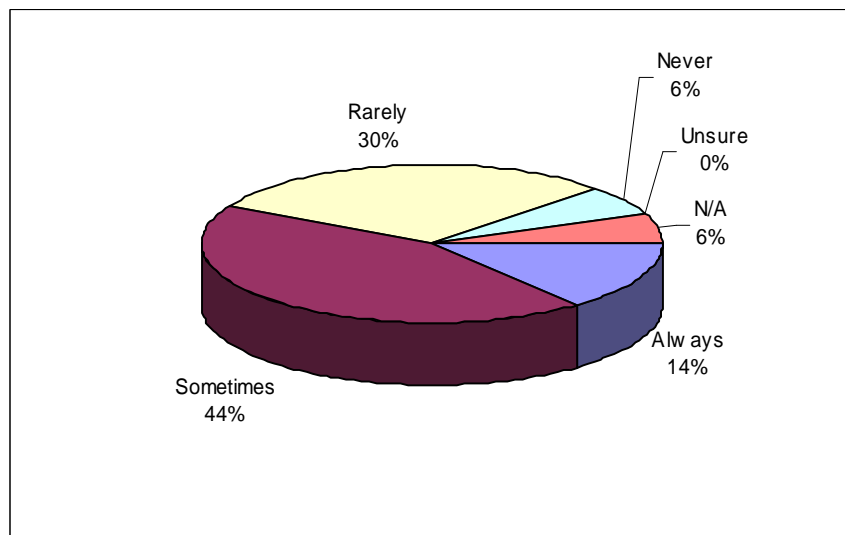
Community, charity or religious organisations

Twenty-five percent (n=15) reported always or sometimes being able to get support from community, charity or religious organisations; 49% (n=29) reported rarely or never being able to get support from them.
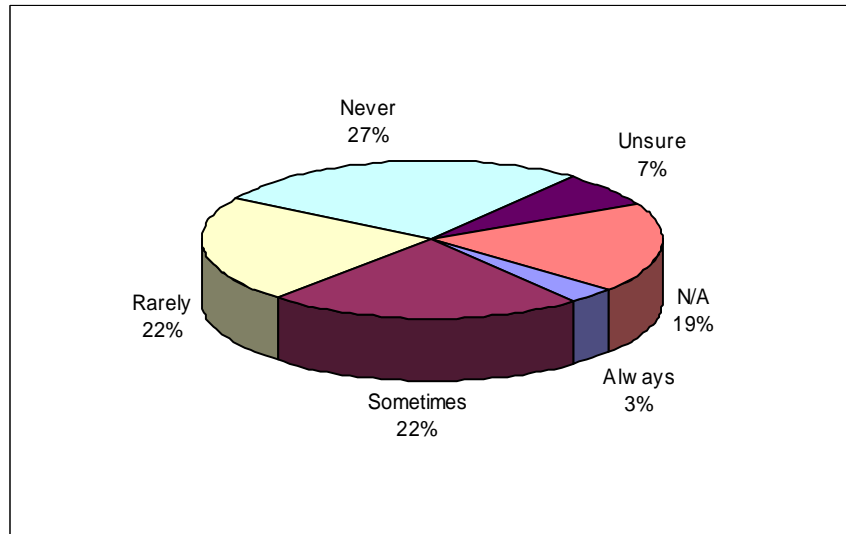
Local council or other government service providers

Twenty-one percent (n=12) reported sometimes being able to get support from local council or other government service providers; 54% (n=31) reported rarely or never being able to get support from them; none of the respondents reported always being able to get support from local council or other government service providers.

Figure 10:   Perceived levels of support from local council or other government service providers
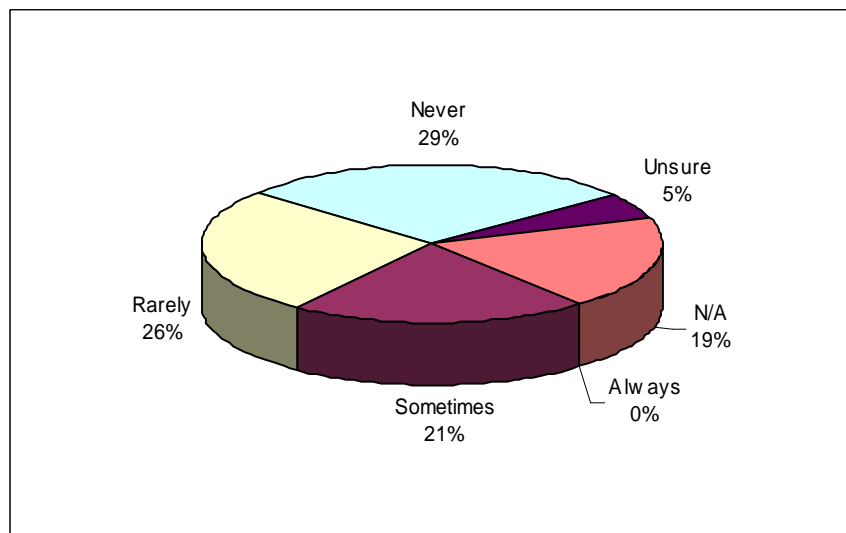
2.4.5. Barriers to social interactions and activities

Respondents were asked to select any factors that made it difficult to participate in social interactions from a set list. Due to an error in the online version of the survey, respondents were only able to select one option. This is likely to have contributed to an overrepresentation in the other (please specify) category.

Twenty-two percent (n=15) reported caring responsibilities as a factor that made it difficult to participate in social interactions; 13% (n=9) reported time; 12% (n=8) reported confidence; 8% (n=5) reported work commitments; 6% (n=4) reported cost; 5% (n=3) reported chronic or serious health condition; 3% (n=2) reported disability; and 2% (n=1) reported lack of knowledge and information about options.

Thirty percent (n=20) of respondents selected other (please specify). 50% (n=10) of these respondents indicated that they would've selected multiple factors if the survey allowed them to.

2.4.6. Satisfaction with social interactions and activities

Respondents were asked whether they were satisfied with the opportunities they had to participate in social activities and interactions. 55% (n=36) of respondents were satisfied; 46% (n=30) of respondents were unsatisfied.

CALD respondents differed from the overall sample with 83% (n=10) indicating dissatisfaction with the opportunities they had to participate in social interactions and activities, and 17% (n=2) indicating satisfaction.

Respondents who reported a total household income (before tax) of <$41,999 also differed from the overall sample with 68% (n=13) reporting dissatisfaction and 32% (n=6) satisfaction with the opportunities they had to participate in social interactions and activities.

2.4.7. Supporting women mental health carers to maintain social interactions

Respondents were asked how women mental health carers could be better supported to maintain social interactions in their community. Some comments from the survey included:

> *Women mental health carers need to be encouraged to take more time for themselves without feeling guilty.*

> *… the more third party assistance, the better the carer's ability is [to] have a more normal lifestyle.*

> *I would be very able to maintain social interactions if my sons were receiving adequate support.*

Promote publicly this need.

Information too would need to be provided. But how you do it, I don't know.

2.5. WOMEN MENTAL HEALTH CARER REPRESENTATION

Unless otherwise specified, the survey findings were consistent across the different demographic groups.

2.5.1. Involvement in the local community

Survey respondents were asked to self-assess how often they volunteered their time, knowledge and/or skills outside of their family on a 4-point Likert scale. 42% (n=26) reported that they frequently did; 37% (n=23) reported sometimes; 11% (n=7) reported rarely; and 10% (n=6) reported never volunteering their time, knowledge and/or skills outside their family.

Respondents were asked whether their involvement in their local community had increased, decreased or stayed the same since becoming a carer. 22% (n=14) of respondents reported an increase; 33% (n=21) reported that their involvement stayed the same; and 44% (n=28) reported a decrease.

CALD respondents overwhelming reported that their involvement in their local community had decreased at (75%: n=9). None of the CALD respondents indicated that their involvement increased. Respondents who reported a total household income (before tax) of <$41,999 also overwhelmingly reported that their involvement decreased (78%: n=14).

Respondents were asked whether they were involved in a local organisation. 56% (n=35) said yes; 44% (n=28) said no.

Of those who said yes, 58% (n=21) reported being involved in a voluntary capacity; 47% (n=17) were a member of a local organisation; 39% (n=14) reported being on a board; 31% (n=11) were involved in an advisory capacity; 19% (n=7) reported being a representative; 14% (n=5) were involved for leisure; and 17% (n=6) specified other.

Of those respondents who specified other, two reported being employed by a local organisation and two other respondents' specified research, policy or other written tasks.

Figure 11: Ways in which ACT women mental health carers are involved in local organisations
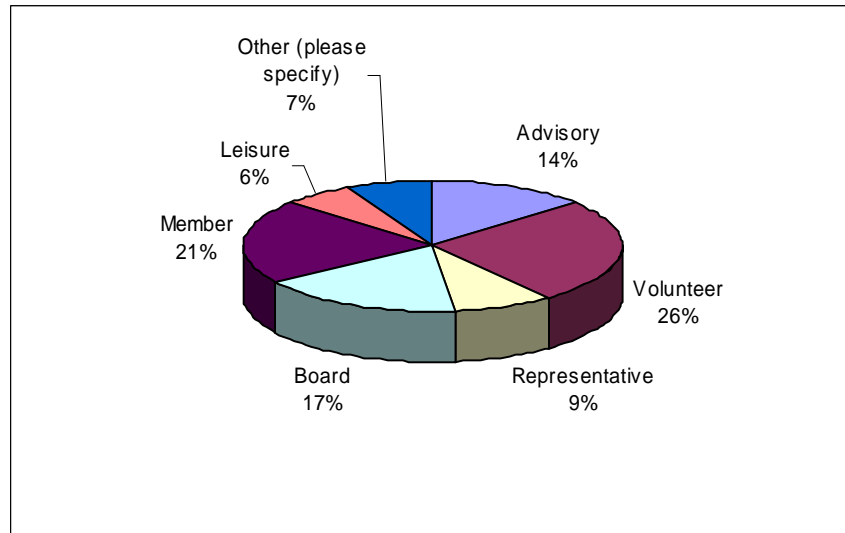
2.5.2. Barriers to involvement in local organisations

Respondents were asked to select from a preset list, any factors that prevented them from becoming involved in a local organisation.

49% (n=16) reported time and caring responsibilities; 36% (n=12) reported work commitments; 24% (n=8) reported confidence; 21% (n=7) reported cost; 18% (n=6) reported a chronic or serious health condition; 15% (n=5) reported lack of knowledge or information about the options; 12% (n=4) reported transport; and 30% (n=10) selected other.

Of the respondents who selected other, two respondents indicated that they chose not to be involved; another two respondents said that fatigue or lack of energy prevented their becoming involved; one respondent indicated that maintaining her privacy prevented her from becoming involved; and another respondent said her inability to secure a reliable wheelchair prevented her from becoming involved.

2.5.3. Participation in local decision making processes

Respondents were asked to rate whether they thought women mental health carers in the ACT were given opportunities to be included in decision making processes on a five-point Likert scale. 29% (n=18) agreed or strongly agreed; 43% (n=26) were neutral; 28% (n=17) disagreed or strongly disagreed.

2.5.4. Supporting women mental health carers to participate in local decision making processes

Respondents were asked to provide qualitative comment as to how women mental health carers can be supported to participate in local decision making processes. Some comments from the survey included:

> *Create a website where they can register to contribute ideas or vote on decisions.*

> *… Some reimbursement of costs incurred in being involved would be helpful.*

> *Their views can be sought through survey's like this…*

> *…Provide transport and even an outfit so they feel they are dressed in similar attire to the others on the committee.*

> *Meetings in the evenings so we can attend if we are working full time.*

> *Provision of more community knowledge about who, what and where women can become part of local decision making processes.*

> *Have forums made available and accessible to all carers (parents, children, siblings etc)*

> *Provide respite services so that they are able to attend.*

> *… Have advocates/support workers attend events with the carer.*

> *By providing more respite care services. If you have other commitments to other family members you can't get your head out the door let alone go to a flaming meetings [sic]!*

> *Better support for our loved ones…*

2.5.5. Barriers to becoming involved in their local community

Respondents were asked to provide qualitative feedback as to the barriers experienced by women mental health carers in becoming involved in their local community. Some comments from the survey included:

> *For me it's mostly time – for some others, I believe it is confidence. I also believe that in the mental health area womens concerns are often dismissed.*

> *Stigma and shame map stop some women participating in their local community.*

> *Cost, access to transport, low income means cheap clothing which excludes Carers, low income means poorer presentation which excludes Carers.*

Their own lack of confidence and skills or age and infirmity. Women who are in paid employment are unlikely to have the time or the energy. For myself I no longer wish to attend meetings held away from my normal area of circulation because I don't want to negotiate new areas in the dark and I don't like the parking arrangements in Civic. Dinner time meetings are difficult for me because I have family responsibilities at the time. Sometimes daytime meetings clash with regular family responsibilities. Besides, [they] are too often boring, ineffective and sometimes distressing.

Not all women want to be in the centre of making decisions through government policies, boards etc. Perhaps there has to be a variety of forums for women to receive support and assistance, and these forums then facilitate information to be provided to government polices and boards etc. All women have something valuable to say and contribute and perhaps more relaxed environments would be a way to engage them in decision making process, i.e. the organisers would pass on the information to relevant decision making bodies.

2.5.6. Supporting women mental health carers to becoming involved in their local community

Respondents were asked to provide qualitative feedback as to how they can be supported to become more involved in their local community. Some comments from the survey included:

Maybe it is my age, but between family, caring and work and some free time for myself I do not know whether I want to become too involved in the local community. If someone asked me to help in someway I would certainly try to help.

Maybe women I have met are very talented, but they do not have the time. I don't see how time can be found for them. Some others may lack confidence.

Clean their houses! Babysit children especially at night so mum's can go out with other adults!

More education in CALD communities about mental health issues so that people understand the pressure of being a mental health carer.

2.6. OTHER COMMENTS OR FEEDBACK FROM SURVEY RESPONDENTS

Respondents were given the opportunities to contribute any other comments or ideas that relate to women mental health carers. Some comments from the survey include:

Women mental health carers are far more than just carers. In my case, I am also a mother, teacher, listener, artist, landscape architect, ecologist, environmentalist, lobbyist, cook, gardener, driver, systems administrator, clerk, accountant, public officer, speaker, Australian plants expert, friend, DIY-er, researcher, statistician, programmer, writer, planner, sister, forward thinker, knitter, Sudoku expert, wordsmith, confidante, reader, photographer, graphic designer, garden selector, occasional garden competition judge, dressmaker, colourist, to name a few.

Many women see their role as a continuation/extension of their 'mothering' roles and don't even consider getting help.

This survey is aimed at carers of someone with a serious mental illness, not someone like me who has cared for someone with PND [post-natal depression] and periodic anxiety. Services like respite etc are not applicable to me or my family situation when my partner is fully functioning at all times, just sometimes affected by anxiety and also had a bout of PND. Is this because PND is not seen as a 'real' mental illness? Or carers of people with more serious and long term mental illness are the ones who really need help? Probably the latter, but what do families who continue to 'get by' do? If my partner had weeks off work because of a broken leg, there would be more support on [offer] than for a period of PND.

There is still alot of stigma around Mental Health and this is compounded by being a ['woman'] and therefore considered to be less-knowledgeable and less able to assist in a supportive non-emotive way. Also, the medical professions still are not aware of the value a MH Carer can contribute to the overall 'care team' process in working with someone with a Mental Health condition.

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