

women's  
health  
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**The Australian Longitudinal Study on  
Women's Health**

**Report 6**

**The University of Newcastle**

**31 May 1997**



# AUSTRALIAN LONGITUDINAL STUDY ON WOMEN'S HEALTH

## 1997 REPORT

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# **JUNE 1997 REPORT**

## **INTRODUCTION**

This is the sixth report on the Australian Longitudinal Study on Women's Health, provided by the University of Newcastle and the University of Queensland, due 10 June 1997, as agreed in the contract between the Commonwealth Department of Health and Family Services and the University of Newcastle.

The contract states that the content of report six is to include:

A For the main cohort studies, a report on:

- selected nested studies exploring particular issues in depth;
- the qualitative and quantitative analysis of supplementary information provided by respondents to the baseline study;
- project operation (management issues, staff, students, visitors, performance indicators);
- plans for the next six months.

B For the special cohort studies, a report on:

- the establishment of the special cohorts and the collection of baseline data from these groups;
- the analysis of baseline data including data books of basic tabulations of all variables and reports on data quality;
- the operations of the National Advisory Committee and reference groups;
- the communications strategy;
- project operation (management issues, staff, students, visitors, performance indicators);
- plans for the next six months.

C For the study as a whole:

- the operations of the National Steering Committee and reference groups;
- the communications strategy;

This report is presented in three parts:

PART A -	Progress at the University of Newcastle
PART B -	The National Advisory Committee
PART C -	Progress at the University of Queensland

## **PART A: UNIVERSITY OF NEWCASTLE**

### **EXECUTIVE SUMMARY**

1 Thirty three researchers are now working with the main cohorts of the Women's Health Australia project. The majority are based at the University of Newcastle, but links are continuing and developing with researchers at the Universities of Melbourne, Queensland, New England and Western Sydney.

2 Analysis of the baseline data is continuing. Three papers have been published or accepted for publication and eleven have been submitted this year for editorial review. The topics of these papers include recruitment methodology, disordered eating, healthy weight, incontinence, life events, the SF-36, iron deficiency, nutrition screening, satisfaction with GP services, hysterectomy and contraceptive choices.

3. Every participant in the study has been sent a newsletter with a summary of the main findings from the baseline survey. Further dissemination of the baseline findings will be by presentation at conferences throughout Australia and overseas during the second half of 1997. (Twenty abstracts have been submitted to conference organisers).

4. A substantial proportion of this report is dedicated to an overview of the supplementary information provided by the middle-aged and older women in response to the question "*Have we missed anything. . .*" which was included at the end of the baseline questionnaires. This report includes a review of the women's comments relating to the five main themes of the project: time use (juggling time and caring); weight and exercise; violence against women; life stages and key events (widowhood); and use of and satisfaction with health services (women doctors, access, costs, services for mental and emotional health).

5. In March 1997 all women who participated in the baseline survey and supplied a contact address were sent an invitation to consent to allow the researchers to access their HIC/Medicare information. Telephone and mail reminder strategies were trialed with selected subgroups. The telephone reminder was more expensive, but proved to be a useful method of 'tracking' women who had changed address since the baseline survey in 1966. To date, consent rates for the three cohorts are 33%, 56% and 53% for the young, middle aged and older women respectively.

6. Ten sub-studies are currently underway on the following topics: health services utilisation (including data linkage with HIC data from consenting women in NSW); tiredness and iron deficiency; disordered eating; legal protection in domestic violence; the health of widows; contraceptive choices; social support for older women; help seeking for emotional and mental health problems; weight change at menopause and the aspirations of young women.

7. The first follow up survey will be conducted for the middle cohort in early 1997. The questionnaire for this follow-up will be developed and piloted in the next six months.

## **1. ADMINISTRATIVE ARRANGEMENTS**

### **1.1 PROJECT STAFF**

The following staff are now working with the research team at the University of Newcastle. Unless otherwise stated, staff are based at the University of Newcastle.

#### ***Investigators***

Professor Annette Dobson, BSc, MSc, PhD (Study Director; Professor, Biostatistics)

Dr Wendy Brown, BSc (Hons), Dip Ed, MSc, PhD (Project Manager & Senior Research Academic)

Professor Lois Bryson, BA, Dip Soc Stud, Dip Ed, PhD (Professor, Sociology & Anthropology)

Dr Julie Byles, BMed, PhD (Senior Lecturer, Clinical Epidemiology & Biostatistics)

A/Professor Christina Lee, BA, PhD (Associate Professor, Psychology)

Dr Gita Mishra, BSc, MSc, PhD (Statistician & Lecturer, WHA)

A/Professor Margot Schofield, BA, DipSc, MCLinPsych, PhD (Honorary Associate, WHA,  
now based at the University of New England)

Dr Deidre Wicks, BA, PhD (Senior Lecturer, Sociology & Anthropology)

#### ***Associate Investigators***

Ms Susan Feldman BA, MA (Alma Unit on Women & Ageing, University of  
Melbourne)

Mr John Germov, MA, PhD Candidate (Department of Sociology & Anthropology)

Dr Justin Kenardy, PhD (Department of Psychology, University of Queensland)

Dr Julia Lowe, MBChB, FRCP(UK), MMedSci. (John Hunter Hospital)

Ms Sue Outram, BA, RN (University of New South Wales)

Dr Rhonda Reynolds, BA (Hons), PhD (University of Western Sydney Macarthur)

Ms Lauren Williams, BSc(Hons), Grad Dip Diet, Grad Dip Soc Sci (Department of  
Nutrition & Dietetics)

#### ***Adjunct Investigators***

Dr Helen Jonas, MSc, PhD, (Turning Point Alcohol & Drug Centre Inc. and Department of  
Public Health & Community Medicine, University of Melbourne)

Dr Wendy Vanselow, MBBS, FRAGGP, DRCOG, BEd (Office for Gender & Health,  
University of Melbourne)

#### ***Postgraduate students***

#### ***PhD candidates***

Ms Kylie Ball, BA (Psych) (University of Newcastle)

Ms Julie Brookes, Dip App Sc (Nursing), BA (Hons) (University of Newcastle)

Ms Pauline Chiarelli, Dip Physio (University of Sydney), Grad Dip H Soc Sci(HProm),  
MMedSc(HProm) (University of Newcastle)

Ms Amanda Patterson, BSc (University of Newcastle), MND (University of Sydney)

Ms Anne Young, BMath(HonsI), Dip Med Stat (University of Newcastle)

Ms Margrette Young, BA(HonsI) (University of Sydney), MSc (Keele University)

Mr Brendan Goodger, BSW(Hons), Grad Dip Hlth Soc Sci (Med Soc Sci) (University of  
New South Wales)

***Masters candidate***

Ms Sue Outram, RN, BA (University of New South Wales)

***Honours candidates***

Ms Stefani Strazzari BA (University of Newcastle) (Sociology and Anthropology)

Ms Gillian Bowes (Sociology and Anthropology)

***Student placements***

Ms Eleanor Gorman (Department of Communication and Media Studies)

Ms Leonie Middlelink (Department of Human Nutrition, Wageningen Agricultural  
University, The Netherlands)

***Office Staff***

Mrs Lyn Adamson	Research Assistant/Publicity Officer
Mrs Jean Ball, B.Math, Dip Med Stat	Data Manager
MsJoy Ellem, BA (Hons)	Research Assistant
Mrs Beverly Parker	Administrative Assistant
Dr Penny Warner-Smith, PhD	Research Assistant
Vacant	Secretary

During 1997, all researchers working on the project were requested to sign a confidentiality agreement relating to the Privacy Act and its implications for confidentiality of the study findings (see Appendix 1).

## 1.2 1997 BUDGET

A summary of the projected budget for 1997 is shown in Table 1.1.

**Table 1.1 ALSWH - projected budget for 1997**

INCOME		EXPENDITURE	
Item:	\$	Item:	\$
Carried forward (1996)	325,604	University of Queensland	<b>187,000</b>
Department of Health & Family Services	900,000	<b>Core Salaries (inc on-costs)</b>	
		Project Manager	65,000
		Statisticians	81,000
		Data Manager	50,000
		Secretary/RA	35,000
		Research Assistants	91,500
		Casual research staff (eg interviewers/ data entry)	40,000
		Scholarships	66,500
		Superannuation	23,225
			<b>452,225</b>
		University Overheads (eg library, info technology, power, cleaning etc)	97,275
		Furniture and Computers	13,000
		Office running costs (eg consumables, photocopier, fax, phone, photocopier etc)	30,000
		Australian Bureau of Statistics	3,000
			<b>143,275</b>
		<b>Pilot projects</b>	
		Newsletter/HIC consent/pilot follow-up	6,500
		<b>Main Survey</b>	
		Printing (Newsletters, HIC consents/surveys)	42,000
		Packing	25,000
		Post/Return post	60,000
		Data entry	60,000
		1800 number	8,000
		Publicity/Communications	5,000
			<b>206,500</b>
		<b>Travel</b>	
		Project (staff establishment/visitors)	3,000
		Uni of Queensland meetings	2,000
		Advisory Group	18,000
		Conference travel	6,500
			<b>29,500</b>
		Sub-studies	<b>89,500</b>
<b>TOTAL</b>	<b>1,225,604</b>		<b>1,108,000</b>
		to be carried forward for 1997/1998 follow-up surveys	<b>117,604</b>

## **2. BASELINE DATA - MAIN COHORTS**

### **2.1 GEOGRAPHICAL DISTRIBUTION OF PARTICIPANTS**

Maps showing the geographic distribution of the participants in the baseline survey have been prepared using the software package Mapinfo Professional (1996) (see Figures 2.1-2.3). Each dot on these maps indicates that there is at least one woman in the study in the designated postcode (range 1- 197, 144, 127 for the young, middle and older age groups respectively). In every age group, the maximum number of responses came from postcode 4350 (Toowoomba and district). There are participants in every State and Territory, and on eight of the small islands which are situated close to the coast. The 14 participants who live on Norfolk, Christmas and Cocos Islands are not shown on the maps. (The single dot in the Pacific represents Lord Howe Island). *(These maps were produced with the expert assistance of Olivier Rey-Lescure).*

### **2.2 QUANTITATIVE DATA**

Data from the baseline survey are now 'cleaned' and entered into the WHA database. There are still some minor programming 'bugs' in the young data for the smoking variables, which should be rectified in the near future.

Data analysis is continuing, with papers in preparation on a wide range of subjects including: life events, SF-36, BMI, smoking, exercise, hysterectomy, aspirations, nutritional screening, dieting, eating disorders, violence, socio-economic status, satisfaction with services, symptoms, help seeking, widows, social support, alcohol, contraception and incontinence. Descriptive papers on the main findings for each cohort are also in preparation. The results of the baseline surveys will be presented at conferences throughout Australia during the second half of 1997. These include the 29th annual conference of the Public Health Association, at which a half day forum on the Women's Health Australia project will be presented. Wherever possible, information from the qualitative data file is being used to illustrate the quantitative analyses.

Following completion of reports on the cross-sectional baseline data, the researchers will be focussing more attention on the longitudinal aspects of the study, in preparation for the first follow-up survey, which will be conducted with the middle cohort in 1998. To assist with this, Gita Mishra, the project statistician, will attend the North American Regional Conference on Longitudinal Data Analysis, which will be held in Missouri in June 1997. This will ensure the researchers are able to consider the most recent analysis techniques for longitudinal cohort data, when the follow-up surveys are designed.







## 2.3 CONFLICTS AND CONCERNS: AN INITIAL OVERVIEW OF THE QUALITATIVE DATA

### Introduction

The questionnaire for the baseline study included a final open-ended question in which respondents were asked, “*Have we missed anything. If you have ANYTHING else you would like to tell us, please write on the lines below*”. In response, some women expanded on the information which they had already provided while others took the opportunity to air grievances, comment on the survey form, or even ask for help. The invitation generated a vast amount of data which was subsequently coded according to a number of themes (see Appendix 2). These qualitative data are rich and illuminating. They convert a series of numerical statements into a community of Australian women whose voices are heard describing the pleasures and pains of their lives.

Information provided by the middle-aged and older cohorts has been examined for the purposes of this report, but some subsections focus on only one of these groups. The analysis of comments made by widows, for example, refers only to older women, while the discussion of weight and exercise focuses on middle-aged women. The table below provides information about the frequency of comments made by each of these two groups, organised into 16 broad themes.

**Table 2.1**      **Comments received by theme**

<b>Theme</b>	<b>Middle cohort</b>	<b>Older cohort</b>
Caring	336	369
<i>Emotional &amp; mental health</i>	866	618
Family relationships	666	693
<i>Health services</i>	757	643
Independence		342
<i>Individual health problems</i>	898	1561
Life history		245
<i>Questionnaire</i>	923	854
Reproductive health	362	80
<i>Social policy</i>	226	171
Stress	416	181
<i>Time use</i>	569	523
Violence	104	53
<i>Weight &amp; exercise</i>	217	281
Ageing	19	
<i>Other</i>	17	169
<b>Total</b>	<b>2525</b>	<b>3007</b>

As the table above shows, the open ended responses represent a huge amount of data and this report is of necessity selective. For example, there was a wide range of comments concerned with health services. Many of these, such as the demand for alternative practitioners, are clearly of concern to a large number of women. Others, such as the

healthcare needs of lesbian women, were mentioned by a minority. For this report, time and space dictated that the focus be restricted and the decision was made to concentrate on at least one issue within each of the five main topic areas of the study: time use; weight, exercise and health; violence against women; life stages and key events; use of and satisfaction with health care services. Other issues will be explored in subsequent reports and papers.

As much as possible, the women's own words have been used as they were written. In order to retain the individual character of the speaker, there has been minimal editing.

This report is an overview which has barely 'scratched the surface' of the qualitative data. Sub studies to come will delve further into the database, looking at issues such as eating disorders, caring and health, social support for older women, and midlife weight gain. These studies will marry the qualitative information with the quantitative analysis to illuminate women's personal experience of general issues.

### **2.3.1 TIME USE**

#### **(i) Women juggling time**

There were 569 comments volunteered by women in the 45 to 49 year age group (mid cohort) which reflected on their patterns of time use. The comments relate mainly to interrelationships between family work, paid employment and voluntary work. It is clear that most of those who offered comments did so because they had a specific concern. The responses confirm findings from time use research more generally and serve to alert us to issues which almost certainly are problematic for many women.

#### ***A climate of uncertainty***

Frequently the respondents highlight the tensions and personal pressures they experience as they juggle their time commitments. Some few women do refer to their recreational activities, but these are in a minority. It is clear that at this stage of the life cycle, for many women, their major concern is just coping with their commitments, rather than considering their own personal development and preferences. The qualitative comments are in line with the findings of recent Australian Bureau of Statistics surveys on time use that have demonstrated that it is women who remain the mainstay of families and take major responsibility for family work, despite their increasing absorption into the paid workforce.

The responses underscore how apt for women is the notion of 'juggling time', and the fact that this has many dimensions. Our respondents provided the following reflections:

It was financially necessary to go back to work when my youngest child (of 5) started school and I'm happy in that I've attained a position of responsibility and commitment, but at which I put in fairly long hours. I am also committed to a number of voluntary community activities and have a frail, elderly mother to visit in a nursing home regularly... I sleep about 5 hours a night only so I can do what I do.

Pursuing friendships and social contacts requires time and energy – often in short supply when raising a family.

Because we had an autistic child this severely restricted my work/career. I was not able to work while he was small he was so demanding and I never had the time, nor the energy to take on outside work.

I go to work, get kids to and fro, feed people and that's it – apart from study – but I guess years ago I did have social activities that were satisfying.

... not in paid employment but juggling many other responsibilities: farm, parents, kids, voluntary work.

### ***'Time for me to have a life'***

Complex, busy and stressful schedules leave many women's own interests in tension with those of their family members. It is not therefore surprising to find that some women are longing for some relief from the demands made on them and look forward to having some time for themselves. Many of the comments capture this feeling:

... can't wait for the last of 5 children to leave home so I can live my own life a bit more.

While I receive the greatest pleasure from my six children (youngest now 18) and have always been actively involved in their activities, I've often felt that my own needs were overwhelmed by everyone else's.

It seems that I have been running around for everybody else all my life. I feel that now is the time for me to have a life.

For other women though, even when their lives are very busy, this is experienced as predominantly satisfying and fulfilling. It is typical that such positive evaluations are expressed in family terms, but they are not confined to this and some appreciate features of their working life even though they recognise it as stressful. One woman, who does indicate she has the advantage of having 'paid help with the housework' describes her satisfaction with her life in family terms, another in employment terms.

I could spend equally as much time in voluntary work outside the home...as I do in my paid part-time employment...I find this a particularly satisfying situation although it leads to over-commitment in terms of time...Both my husband and I are involved in school activities and I believe this is the basis for what I regard as a sound and enjoyable relationship with our two teenage daughters.

My job (teaching) is both unremittingly stressful and a source of pleasure and personal achievement.

### ***Uncertainties in paid work***

Another theme is the necessity for many women to create new careers for themselves in their middle years when, having adopted the role of homemaker, they had not necessarily foreseen this. Women find themselves having to reorient themselves to paid employment with some undertaking study to better equip them for the workforce. In an uncertain economic climate in which jobs are scarce, this can be doubly perplexing, though as the first respondent points out studying also has its rewards.

People my age are suffering because they (society?) changed the rules when we weren't looking. We are still relatively young, with a lot to offer, but because we took time out to have our families, and never imagined we would want or need to work, now we have no

place in the world...I have done well at my studies and am now engaged in a higher degree...which I think is very worthwhile and will be enjoyable...but success has been hollow since I lost my job (through no fault of my own). The career path I thought I was following no longer exists... Best I can get is a bit of casual work in an area I don't really like.

There is a tremendous conflict between being a "home" mother and feeling used by working mothers in that you are the one who helps in the classroom, attend meeting, work on committees, make a huge donations of time and effort and then one is "too old" to get a job and retrain.

Many other respondents draw attention to the pressures they have been experiencing because of the uncertainty about employment, for themselves and members of their families, in the current economic circumstances.

Job uncertainty for my partner and myself creates a lot of stress...

I have just lost one job (12 hours casual teaching. Yesterday applied for Librarian job (part-time). I have a sole parent pension but it was cut back due to work. Got my Grad Dip Ed at age 48.

My working experience in the last twelve months has been with a temporary agency on a casual temporary basis.

Since moving to this town I could only find part-time employment, but I am hoping this will change as we are moving again soon.

Because my employment as a teacher is on a contract basis, I am under pressure to perform at a very high standard, causing extra stress...I also do many hours of my school work at home.

The uncertain economic climate has exacerbated a particular form of time stress experienced by some women who are involved in family businesses. Women involved with farming face distinctive problems.

... we own and run our own business and have done so for the last 8 years (7 days a week) 2 shifts most days...hope to sell in next twelve to eighteen months and have more time together with my husband...Recreation and travel would certainly be welcome...

... rural women [need] to work in paid work off farm and work during other daylight hours and weekends on farm work i.e. some women are working 40 hours paid off farm work and 30+ hours farm work – for no gain other than interest payments.

### ***The strains of sole parenting***

Sole parents often find it an additional strain to have constant responsibility for caring for their children. For some, nonetheless, this situation is accepted as preferable when the former relationship was violent or strained. Lack of available substitute child care in particular, when children are sick, is a pressing problem for sole mothers.

The last three years have been somewhat difficult as I separated from my husband and for most of the time I have been the person looking after 2 school age children... It is tiring at times when working full-time, and it is difficult to meet new people and re-establish a life.

Illness of children (even trivia) is a major stressor due to my full-time employment and lack of child care for them if sick. [also] involved in union activities at branch and state level. Would love to engage in vigorous exercise (have always done so) ... but no time, no child care' (sole parent whose ex spouse is alcoholic and was violent).

## ***Conclusion***

Participants' reflections on their time commitment reveal that many women are experiencing pressure. Many of the comments reflect well established patterns which have been demonstrated by both Australian and international research over many decades. This research has shown that because women are disproportionately responsible for family work, if they add paid work to this they are likely to be time stressed. However, the uncertainties about employment must be explained in terms of the contemporary economic climate. High levels of unemployment and a downgrading of employment conditions as seen in more casual, temporary and part-time work, add a new element of anxiety on top of the time pressures which many women experience.

### **(ii) Tensions in informal caring**

This discussion of women's experiences of caring focuses on caring responsibilities beyond those concerned with what is perceived as the normative 'woman's role', ie caring for a working husband and growing children. The quantitative data show that about 20 per cent of middle-aged women and about 17 per cent of older women regularly provide care or assistance to another person because of their long term illness, disability or frailty. For middle-aged women in particular, this involvement is often additional to their 'normal duties'.

Three hundred and sixty-nine older women and 336 women in the middle-cohort made comments which were coded under the theme "caring". The majority of these women were caring for their disabled or sick children or ageing parents, but others were looking after their husband, siblings or grandchildren, or providing support to community members. The comments made by respondents confirm conclusions drawn by British authority on women and caring, Clare Ungerson (1994). She points to 'deep and possibly ineradicable conflicts between carers and cared for'. The following extracts from the qualitative data show that in Australia too there are fundamental conflicts of interests and concerns.

## *Conflicts and concerns*

### *Emotional conflict*

One dimension of the conflicted nature of caring is the personal relationship between the carer and cared for.

I care for a severely disabled person at home who needs 24 hours per day care. Nothing was asked (about) the stressful relationship one has with a disabled person living in the same dwelling...

I have a 17 yr old son with an intellectual disability who has severe behavioural problems which have contributed to family relationships and amount of social contact over the years.

My (invalid) husband is very demanding and I would love to have a holiday away from him for just a couple of weeks, but placing him into somebody else's care is virtually impossible.

I am caring for my husband who has had a stroke 6 years ago and memory not so good, also walking in a frame. He can be very demanding on me. Sometimes feel like I need a break.

### *Caring and life stage*

The concurrence of menopause with caring responsibilities for parents can exacerbate the demands on women's health.

I am sure I'm not alone with the experience of the onset of menopause coinciding with the failing health of parents... In my experience my Dad suffered ill health for years, then suddenly it was my Mum who was given the 'death' sentence. She hung on for 4 months only to have my Dad die, then Mum 6 days later ... With the death of my father I thought I would go crazy with grief and worry. Almost 2 years down the track I can [say I'm] still not over the whole episode.

I have a professional career: travel interstate once a week - international once a quarter. I commute 100k per day to my office. My mother lives with me 3 days (weekends and Monday) returning to nursing home when I am interstate. The last 2 years have been stressful with elderly sick/frail parents and no back-up assistance from family who all live interstate. Adding to this was bowel surgery and menopause

At the time of life I face the problems of 1)menopause, 2) aging parents... Late last year my father had a serious stroke. My mother became depressed as a result of the stress of caring for my father. I was forced to take leave from work to care for them.

When care is needed by both elderly relatives and children, women are potentially torn between conflicting demands.

I have experienced the death of a son aged 5 (14 years ago) and both parents in the last few years, one of whom I cared for ... many women I know fear a great load in dividing time between needs of family and elderly relatives.

I am one of many such parents who have extreme stress by having a disabled daughter living permanently with us at home. In the past we had adequate respite to help us with this situation, but recently this has not been the case. In addition, we have my ageing parents living nearby who are now putting extra stress on the family with their medical conditions and reliance upon us to provide support with transport to specialists, etc., household maintenance, and general care.

When children leave home, there is an expectation that there will be more time for oneself. This does not always occur. For older women who have often already raised a family there can also be an unforeseen demand to return to the caring role when grandchildren need attention and support.

I help to care for my eleven year old granddaughter, who is an only child in the custody of her father. I drive her to and from school, prepare their meals, do their washing and housework. Help her with her homework and school activities and give her moral and financial support.

Comments such as the one above give the lie to the stereotypes of older women which focus on their increasing need for care. Too often they are seen at least as non-contributors, at worst as a chronic drain on resources, and yet the reality may be the opposite.

... I am a very healthy 74 year old... Reared 7 children on my own & have 21 grandchildren, eldest 21 years old. I help all - sew, knit, crochet, baby sit when needed... visit hospitals & aged care homes & look after and visit any elderly people living alone who I visit & shop for if necessary.

### ***Caring, and gaps in the healthcare system***

#### *Advocacy*

Women often find that 'the buck stops here', and feel both besieged and isolated by their responsibilities.

This is just so traumatic and if you happen to be an only child the problems lie heavily on your shoulders.

The carer must often also be adviser, decision-maker and advocate for the cared for. For example, when there is a need for nursing home placement, in addition to providing continuing physical and emotional care for an elderly parent, the carer is confronted with the reality of the demand on hospital resources conflicting with the scarcity of nursing home beds. The complexity of administrative and bureaucratic processes associated with the search for a place to which the parent can go can be frustrating, bewildering and time consuming.

I was being told that my Mum, however ill she was, had to go out of hospital and into a nursing home, but there were no places for her. And it seemed to be up to me to find somewhere for her to go.

Concern:- the effect on the family, workplace and personal health and wellbeing because of being a carer for an elderly mother suffering a form of Alzheimers. The frustrations and anxieties of organising and finding out services available for assistance in keeping her at home - and eventually into nursing home care. The on-going stress of being an effective advocate for her and the fear of suffering the same fate.

### *Lack of respite care*

Caring is often quite literally a full-time job: 24 hours a day, seven days a week.

We are both retired, but my husband has bad health and can't get about much, he has to take 16 pills a day, and I have to help him in every way. I also have a big house to keep clean, and do all the gardening, so I don't get any time to myself, and often feel very tired.

Many women wrote of the lack of support for carers, particularly the lack of respite care, and their wish for additional support from family members or community services.

Although we attend meetings to achieve more housing and respite care for our daughter and others in similar circumstances we do not appear to achieve our objective and this is very frustrating and worrying.

Having old/ill parents I'm finding support groups in the community/council very lacking or very hard to access and very insensitive in their responses.

My husband is legally blind and I have to do all as my family are 300 k away and there are no services here. I am the only driver and he depends on me but my family are very supportive but work keeps them busy. I recently went to a Carers Meeting and was told I was not eligible for any help re (yard, garden, lawn, etc) and to let the house fall down.

There are extra problems for rural carers.

As you can appreciate, living in the country means travel to city for all of the medical problems associated with my daughter and also my parents

... in the country the facilities are just not there.

More care should be available for home care and assistance in the country, both for recuperation purposes and assistance with elderly.

My husband has suffered three strokes and I am the carer. The apparent curtailment of health services ie. hospital, home care etc is very worrying. Distance is also a problem for country people when it comes to specialised care.

One woman, however, commented on the progress in service provision, albeit progress in slow motion.

We have a son with a mental disorder and that creates a lot of anxiety and tension in our home. The feelings of isolation and helplessness are often evident but health services for people like us are gradually improving and the barriers in society are very slowly coming down.

What is hidden is the 'backup' support that women often provide to friends or relatives who are carers. When this support is mentioned, it is not by the 'backstops' themselves but by carers who say that they rely on relatives or friends for respite care and support, and invariably these supporters are women.

For the moment my wonderful daughter is able to take a day off once a week to take charge of her dad whilst I get the groceries, bank, hair cut, etc...

As I care for my elderly mother, and have no family in Australia other than my son and daughter, I would like health care workers to be able to stay at my home overnight if I need to go away. At present this care is not available (to my knowledge). The elderly are expected to temporarily live in "respite" homes or hostels, which these days are under much scrutiny and suspicion as to their real care for others. This is an option I would not contemplate for my mother. I therefore need to rely on my daughter or friend to stay at my house in my absence or leave my mother (who is classed as frail) on her own to fend for herself. The other alternative left to me is to remain in my house every night, every week, every month, for every year! This is impossible.

### ***Effects on the health of carers***

#### *Physical demands*

Caring for others makes demands on women's physical health.

Have arthritis - taken 8 Panadol tablets a day for years. Told by Dr to cut down and feel better, but ache (from lifting husband from bed to chair, toilets for years)

Both my younger daughters are multiply disabled. Sleep and back/joint problems stem directly from their care.

My health declined from being a healthy active person through years of caring for a very ill husband.

Because my husband has terminal cancer and is bed ridden I am unable to go outside to get sufficient "proper" exercise.

I have very little time to follow my own interests and being now 71 years old I find my energy decreasing.

... being virtually house bound and social life almost non-existent, I feel that my health will surely deteriorate.

I want to be as supportive as I can and I think my own health is suffering as a consequence.

Caring for him over such a long period had a very wearing effect on me physically and my concentration etc were affected.

Having to physically restrain him at times may also have a bearing on my physical deterioration...

I have a 14 year old son with severe autism and intellectual disability. He is presently in permanent care which is not satisfactory to his needs and causes me severe stress. In my work as a consultant in behaviour management for adults with autism, I come in contact with many families where the health of the mother has been similarly affected. The problems of children with disabilities are very often borne solely, or in the main part, by the mother. At present I attribute my eating problems, overweight, chronic depression, sleeping problems and fatigue, to problems associated with my son's disability.

I have found that since I am working part-time as an enrolled nurse and looking after my partner who is totally reliable on me for everything, and this has been going on for the past three and a half years, my health is taking a beating with me. My partner is confined to a wheel chair and can not do a thing for himself.

My husband died of lung cancer 12 months ago. My mother also died of lung cancer 9 months ago. I nursed both of them at home till they died. In that time my health really deteriorated. I admire older women who do the same thing because I am only 48 and I know how tired and stressed you can become.

### *The stress of fearing the future*

A particular cause of stress for carers is anxiety about the future. This is felt by parents when they contemplate the future of their disabled child, or by family members who fear that they will not be able to afford to provide care.

Continuing worry about his present circumstances and what will happen to him when I die has devastated my health, fitness and emotional wellbeing.

... not excluding emotional stress when the future is always a worry to ageing parents.

I have my mother 95 in a Nursing Home which I find hard to cope with because there is so little I can do. I have accepted this. My worry is that what will happen if this should become too expensive for us to cope if this is taken away by the Government

I "worry" about their future...

I have a daughter living with my husband and myself who was brain damaged at birth (1962) (sub dural haematoma). It is of great concern and worry to both my husband and self as to our daughter's future when we are no longer here to care for her.

My health and well being are directly related to that of my children two of whom are disabled, and their needs are definitely not being met! ... I have for many years now attended a psychiatrist who helps me deal with the stresses of caring for them, and facing their futures, which most of the time, appear pretty grim

### *The nature of caring*

#### *A long term commitment*

Caring is more often than not a long term commitment. Whether women should bear such burdens is one question, but how they manage to do so is another question entirely. One respondent, for example, spoke of a son with cerebral palsy, a second son with schizophrenia, and an epileptic husband.

As well as working for the past ten years, I have been a carer for nearly 30 years - I'M TIRED. [emphasis in original]

The long term nature of this commitment draws on women's health and resources. However, it can take not only their time and their energy, but their social relationships, their pleasures, their holidays, and their foregone income.

I have spent most of my adult life caring for other people. Cared for my mother for 20 years then I had my brother ill for another 20 years.

My husband passed away in March last year after me looking after him 24 hours a day for 10 years... I was very tired but I am getting much better now.

...regarding my son's disability. It is also because of his intellectual disability and extremely challenging behaviours I do not have much spare time. We do not have overnight respite and have not been away from the family home on vacation for 20 years.

### *The costs of caring*

#### *Costs for carers: savings for government*

Carers are almost invariably disadvantaged economically by their caring roles. The motivating force for women continuing to care is often that there is simply no one else to do this work which is grossly undervalued and under-rewarded. Often they cannot work outside the home and yet their 'labour of love' represents a cost saving to the wider community.

I do the work of an occupational and physio-therapist, nurse, housewife, psychologist, chief cook and bottle-washer, gardener and finance manager and for that I receive \$57 a fortnight + \$28 a week. It's cruel that "carers" have so little value in the Government's eyes. My job as carer is 24 hours a day every day with no respite, no holidays and yet I'm saving the Governments thousands of dollars as are many other carers because we do CARE. We've been in situations where there's not been enough money to buy food and we've had to live on what meagre items were in the cupboard. All of this financial situation is my main stressful problem, ensuring my husband has the best possible quality of life - for he has nothing else.

Very dissatisfied with government respect and acknowledgment of carers of elderly parents. My disabled elderly mother could not live in her home without my care, yet I am entitled to no help from government.

... when attempting to be classified as a carer for a measly few dollars a week (my mother could not be left alone at that time), it was impossible to convince the medical hierarchy of this reality...

Also I like you to know I caring for my husband. He is stricken by Paget's disease. - I receive from QLD Health department \$57.10 a fortnight domiciliary Nursing care benefit to look after my husband. It is a peanut . If I put him in a nursing home will cost government a fortune.

Take elderly and disabled residents in my village to doctors, dentists, shopping etc, plus small items of medical assistance, applying plasters, rubbing in arthritis cream etc... I run an old bomb of a car and expenses connected with this are difficult on a pension. But I cope.

The financial aspects of being a carer appear to be grossly underestimated. They extend to transport costs, building on to the family home, and taking time off work.

... my husband has Alzheimers. He went beyond my care and for the last seven years I travel 95 k each way to visit him in hospital twice a week (used to be three times but now too expensive).

Having my parents come to live with us and having to do major extensions to our house due to their disability and having to scale back work to care for them is costly, and for the first time our finances are stretched.

Most of the stress related to caring for aged parents over the past 5 years has come from no public transport to doctors, dentists, opticians, specialists. My husband and I have had to constantly take time off work to help them. It also caused much distress to Mum and Dad. As our combined salary is just over the amount allowed we cannot claim Austudy for uni student. We have no life of our own because of lack of funds. Can't even consider a drive - petrol too expensive in country.

### *Indirect costs*

There are costs to carers beyond financial demands. The effects extend to stress on family relationships and marriages and to constraints on friendship and social life.

My husband has Alzheimers disease and severe dementia so it means our social life is very curtailed. He does go to respite care 2 days each week which does give me sometime to myself.

At present caring for husband with terminal illness therefore unable to take part in social activity.

Personal relationships, activities and family relationships are nearly non existent when caring for these people. I have made many sacrifices in my life caring for my child.

Caring for a child like this places enormous stress on a woman - in my case it probably was in part responsible for my marriage breakdown and I've found that you really become the sole parent of a child like this. Since separation my ex-husband has not had anything to do with the disabled child. Emotionally, I find the lifelong responsibility of this child overwhelming and very restricting in any changes I might care to make, eg. returning to study, leaving the district, etc.

I feel you should have had something more about people like me who had to give up their home and move about 800 k away from family to look after ailing parents. This has put stress on me.

On a more positive note, some women in the caring role have learnt to deal with new situations.

At my age (72 yrs) I and many of my contemporaries have a different role in life; that of a carer. While my spouse is physically fit - his mental condition has deteriorated. Therefore I now do things that I didn't think I could do in my younger years - the finance, driving and managing, in our case the farm. A plus here is that I have found a strength that I didn't know I had. A minus is that we now have a very limited social life as at this stage, my spouse is more secure and happier in his own environment.

### ***Different dimensions of caring***

The voices of those who need care were also heard in the qualitative data.

I do the shopping for 5 people on a bike with a backpack. I am the only Mum who doesn't drive her kids to school. Picking them up after school for doctors/dentists is a nightmare!.....What I'm trying to say is : - it's difficult being a disabled mother of normal children these days!

I have arthritis and Parkinson's and most of the time I am unable to walk, and that keeps me depressed about help. I could do with any help.

The dignity of privacy is very important and should not be overlooked. There is a need for places where the sick, the mentally ill and the elderly can be cared for sensitively and where their dignity is a high priority along with comfort and privacy.

### ***Conclusion***

The conflicts in caring involve tension over financial interests, the distribution of time, of lost opportunities, of inability of the carer 'to adequately meet the needs of the cared for'.

The stories of the lives of women who are now middle-aged and older demonstrate clearly that caring became a way of life for many women of those generations. However, as women increasingly enter the labour force and their ability to provide unpaid care diminishes, there is a growing need to examine different ways of providing care. For example, it is suggested that self help groups are beneficial for some people but these comments underscore the need for further research and policy development in the area

Arthritis seems to be a special worry to older women particularly widows who do not now have support of their husbands. Most of the younger generation are in the work force with mortgages and children to educate so really have so little time for themselves let alone look after an elderly relative. More research is needed into the funding and benefits that self help groups could provide.

A sub-study on the health needs of carers is planned to begin later in 1997. This study will explore women's experiences of caring, and the effects of caring on women's health, in greater detail.

### **2.3.2 WEIGHT, EXERCISE AND HEALTH**

This section of the report looks at what middle-aged women say about weight and exercise. Two hundred and seventeen women in this cohort wrote comments about these issues. The majority of the comments were about problems with overweight and weight management, reasons for weight gain, and reasons for lack of exercise.

## *Reasons for weight gain*

Individual reasons for weight gain were confidently identified by many women. Menopause and hormone replacement therapy were foremost amongst these.

I'm currently 3-4 years into pre-menopause and coming to terms with being overweight. Beginning HRT was the time of my largest weight increase apart from pregnancy. I am considering stopping HRT now and returning my body to "normal".

Hormone replacement therapy. This treatment over the past 16 months has given me a 5 kg weight gain (either the HRT or Menopause itself).

I was put on HRT without any tests to see if it was needed. I put on a lot of weight, and was told to buy bigger clothes (female doctor 60+ yrs). Been eating a lot of chocolate etc. and put on lots of weight.

Several women identified other forms of medication as a cause of weight gain. Medications for problems such as asthma, rheumatoid arthritis, Graves disease, thyroid disorder and nervous breakdown were specifically mentioned. One woman wrote of her struggle with rheumatoid arthritis, and the effects of the medication on her weight:

My weight gain is due to cortisone. Not only oral but over the last 2 years I have had 4 x 1000mg intravenous pulses of cortisone, plus 6 weeks of chemotherapy in an attempt to stop joint destruction. So my weight gain is a world of its own. My medical regime includes a crew of 6 specialists all of whom are very supportive and often express their own frustration at the inability of science to find a "cure" for RA. Good luck in your research.

Heredity was mentioned as a reason for weight problems by two women.

In the section concerning weight gain, no mention was made of the family genes. All members of my family became overweight in their mid thirties and we all continued to gain weight regardless of diet.

I firmly believe weight is hereditary and grandma was overweight.

Another attributed her problem simply to ageing.

Weight gain - reason: age - every 5 years seems to bring on a few kg and a few cm.

Many women identified emotional issues as reasons for weight change, including stress due to marriage breakdown and grief.

My drastic weight loss was due to my marriage break-down.

But having lost a 23 year old son four and a half years ago, has had a great effect on my health. It has affected my weight

While energy balance and its contributors, eg (lack of exercise, too much food) were identified as causes of weight gain by several women, others attributed their weight problem to depression or the emotional stress of women's caring roles.

Intractable obesity. This is a source of enormous distress to me: in spite of exercising 1-2 hours every day, eating a low fat, high fibre almost vegan diet, my weight continues to soar. This may have an emotional base. While my physical health is good, my emotional

health is appalling - I have suffered more or less continually from depression for the last 3 years. The weight problem exacerbates this greatly and it is a vicious circle. I have had several deeply traumatic emotional events in recent years which have impacted seriously upon my health.

Overeating was the overt "reason" but my opinion is that the overeating was a symptom, and that the underlying reason was coping inappropriately with the stress of finding myself at home with small children and few social supports, and with no idea of how to help myself.

I have a 14 year old son with severe autism and intellectual disability. The problems of children with disabilities are very often borne solely, or in the main part, by the mother. At present I attribute my eating problems, overweight, chronic depression, sleeping problems and fatigue, to problems associated with my son's disability.

There were connections made between weight and working outside the home.

The key to better health for me is weight loss and manageable work hours.

For women, 'manageable' work hours probably means having time available outside work for exercise, as well as for shopping and preparing healthy food. Although these issues were not specifically raised, another woman identified her weight problem as a result of returning to work.

My weight is a constant concern to me, although I have not ever gone to great extremes to lose weight. Over the past 3 years I have lost 10kg through exercise and diet but have slowly put most of it back on again since I returned to the workforce after 7 years on family leave.

### ***Sources of help for weight problems***

Several women wrote about their experiences of seeking help for weight reduction. They specifically mentioned the weight loss industry, general practitioners, and alternative health practitioners. Comments about the weight loss industry were generally supportive.

Joining the Weight Reduction Club two and a half years ago was the best thing that ever happened to my health. I now have self confidence which I never had before. I had tried diets and many other ways to lose weight but very unsuccessfully I wish I would have joined this club many years ago for I would have had a much happier and healthier life, longer.

I am currently attending Weight Watchers, 6.1kg off in 6 weeks with diet and daily 5km walk.

As a current member of Weight Watchers I expect my wellbeing to improve as my weight decreases.

Three women wrote about negative experiences of help for weight loss from general practitioners.

Sometimes you are not always taken seriously, (by the GP) or else you can be told to lose weight. If you are already on a diet this is not easy.

The medical profession has been useless to help me - I've had to work out how to feel good by trial and error, and naturopathic help, and prayer.

Taking Clomid and my metabolism changing, my weight was increasing at a rapid rate. I was starving myself to try and stop it. One stupid doctor said to me "that I was eating too much". I was extremely upset at this attitude, ignorance and arrogance. A friend recommended the world's best acupuncturist and her treatment finally stopped my weight increase.

One woman suggested that weight problems need intervention or assistance from several sources.

I do not feel that the medical profession treats this as a serious problem with needs for many areas of assistance, eg. psychological, dietitian, physical trainer. The problem needs to be helped by a combined treatment as the ad hoc manner now employed leaves the patient floundering. Most wouldn't be obese if they could help THEMSELVES. Diet "clinics" again only take your money but seem unable to address many facets of the issue.

The quantitative data support this woman's observation that women living in rural and remote areas are heavier than their city counterparts. She commented on the lack of available help in rural areas.

We have been living in a rural area only 3 years and I have noticed women here seem to be a lot more overweight than women in cities. They also have less resources to do anything about it.

### ***Smoking and weight gain***

The apparent paradox between the ill-effects of smoking and weight gain was recognised by several women. The last of these comments also raises the issue of lack of help for weight problems in country areas.

I have gained most of my weight since giving up smoking 2 years ago.

Two and a half years ago gave up smoking- put on weight. One year later started smoking again, lost weight I put on.

At the time of my depression my husband & I both gave up smoking (bad idea) & I put on 15 kg. I have since lost 5 kg & have tried again to give up smoking (unsuccessfully) with Nicotinell patches. Not enough willpower I guess.

I wage a constant battle between giving up smoking and gaining weight. Normal weight (impossible to sustain when not smoking!) = higher self-esteem (v. important to me) BUT smoking = health problems in the future! Very difficult to get on-going support in the country.

## ***Weight cycling***

The problem of weight cycling was also raised; several women wrote about their experiences of weight loss followed by gain.

I would really like to lose and maintain a lower weight - due to health reasons - I find this extremely difficult as have tried and failed many times in the past.

I have 5 or 6 times gone on diets and lost some weight but always ended up heavier than when I started.

I consider that the majority of my health problems are related to my obesity. I do now, and always have found it difficult to lose weight then keep it off. I am on the true cycle of losing weight then gaining more.

The difficulties of maintaining weight loss were also described by one woman, in relation to complex interactions between life events, emotional well being and weight control.

My 1st born child a daughter was born 23 years ago, but was born with encephalic condition, and died soon after. This resulted in a nervous breakdown, and then the weight problem started. My husband and I coped fairly well then, and we had 2 other healthy daughters, but then 14 years ago he walked out, more weight went on, then I joined weight watchers, lost 5 stone, but now have put it all back on again. I have been through a few long term relationships, but I'm on my own now, and coping very well, but still very overweight.

While the majority of concerns in this area were about weight gain, one or two women identified unwanted weight *loss* as a problem. Reasons included overseas travel, Ross River Fever, cholesterol diets, diabetes, breast feeding and stress.

At age 27 I travelled overseas for 3 months and lost weight as a by product of extensive walking while sightseeing, and due to dietary limitations in certain countries visited.

I have just come home after being away for 3 months - working as a seasonal fruit picker - 2 months on a blueberry farm, 6 days vineyard, 18 days apple picking. Because of the constant physical work and I ate "heaps" of fruit and I lost a lot of weight

Five women made comments which illustrated a generally good knowledge of the health consequences of remaining overweight

I would like to get my weight down to about ten and a half - eleven stone. I think I would be fitter and healthier.

A lot of health problems relate to being overweight - and it seems an insurmountable problem.

I feel that I am in poor health because I am overweight and need to take more exercise.

I also have my blood pressure checked about twice a year, mainly because my parents have had a problem. Other than that I feel that I am pretty lucky and I know I will be even better if I can get my weight down!

My goal is to have a healthy old age - that's why I work out and eat less fat.

## ***The problem of the 'beauty myth'***

Some women simply did not want to weigh themselves, or did not wish to disclose their weight. Of the 14,205 women who answered the survey in this age group, three per cent did not answer the question about current weight. Some of the comments about this issue were:

Sorry it's taken so long to answer, but I found it very difficult to get on the bathroom scales to see how much overweight I am. I'm definitely depressed now, so next time I'll be the one using all those terrible methods to get down to the models' weight.

I have not put my weight and not answered some questions re: same because I find it a very personal data do not like discussing it with anyone

However, other women appeared to be tired of the constant messages they are receiving about being thin.

It angers me that it is always portrayed that to be healthy you must be skinny. For me, it was the reverse. I lost weight and my life became a misery and ill health. Why can't people accept that we are all different and stop trying to categorise everyone.

### ***Acceptance***

Other women said they no longer worry about their weight; so much so that they were unable to provide an estimate of their current weight.

No scales at home. Will call with weight when I manage to get near a chemist and weigh myself. (*she did!*)

We do not have any scales so therefore do not know weight - tell by how clothes that fit and how I feel.

I didn't put my weight in as I don't know what it actually is, however as my dress size is size 26 you can tell that I weigh far too much

Several women wrote about their acceptance of their weight problem, sometimes after several attempts at weight loss, or as a result of a change in a personal relationship.

I have a serious weight problem that should worry me but it doesn't. Sometimes I worry that I just might be struck down with heart attack or stroke but not strongly enough to motivate lifestyle changes. And basically totally lack confidence in my ability to do anything about my morbid obesity. I've failed at all forms of weight control including stomach stapling and group therapy, so I'm adjusted to just being me.

I'm a very happy person since my second marriage 6 years ago to a wonderful man, hence no stress. I look after a 26 year old son from 1st marriage who is mentally handicapped at home and my days are very full and enjoyable, would not change anything. You will find me a boring subject as I'm happy, healthy and overweight and enjoying it. My husband loves me just the way I am.

I consider myself very overweight ( take a size 22-24 in clothes)- my only sister is about the same size - I never weigh myself and do not take any dietary action. We eat a healthy diet with mostly home- prepared a lot of home-grown food including our own meat. I do eat lolly bars at the rate of 1-2 a week . We eat dessert rarely.

One woman summarised this whole vexed issue of weight acceptance nicely with the following comment.

... regarding weight gain. Always a vexed question for the over 45s!! As women reach menopause waistlines widen (apparently out of our control) and it seems impossible to keep the shape of yesteryear. Even with an active lifestyle it is a constant battle of the bulge. Perhaps there could be more education for women explaining the process of change of body shape. I'm sure it would lessen the anxiety and the emphasis our society tends to place on the body beautiful. I'm not advocating being overweight - but rather an acceptance by women of the shape they are.

### ***Middle-aged women and exercise***

As one strategy for maintaining health, and healthy weight, several women recognised the need for regular exercise. The benefits of regular exercise particularly as they relate to weight control, were mentioned by two women.

At 46, I think (know) my body is as good as it was at 16. If everyone kept their weight down (not underweight) and exercised 3-4 times a week, they would stay healthy. Everything else falls into place if people exercise.

I would like to lose weight but do so by increasing exercise and omitting luxuries such as ice cream, sweets and fats on food. I'm too fond of food to diet.

One woman wanted to clarify the distinction between health and *fitness*.

I am in good health but not FIT because I don't get nearly enough exercise

### ***Defining exercise***

The issue of what constitutes vigorous and moderate exercise was questioned by a few women. Some described participation in traditional sports or fitness activities, while others described activities which they thought should count as 'exercise'.

For 20 years we have been engaged in 5 days a week vigorous exercise, eg. running, cycling, horse riding.

I believe that I am very healthy (and happy) because I resolved at about age 11 or 12 not to get overweight. I have played tennis several times a week for years both competitive and social for fitness and to control my weight. I have also jogged over the years and taken part in aerobics.

I play golf 3-4 times a week at a very slow pace but still puff and pant.

We have 2 teenage daughters (18) & (15) still living at home. I work part-time so life is always busy juggling commitments. I have joined a gym doing fitness circuits, weights and aerobics and I am attempting to walk several times a week. I am also passionate about gardening so I do get some exercise there and I'm sure it helps my flexibility.

Sex had always been a wonderful way to get vigorous exercise which would last 20 minutes or more which raises breathing and heart rate etc.

My vigorous activity is on a pick and shovel, rather regularly, this does cause back strain.

I live on a 500 acre farm - thus my exercise is lifting walking, running related to farm activities - cattle, sheep, horses. Morning and night feeding.

Although I don't play sport, we have a small farm and I have times of extreme exertion (puffing, panting) but not sustained for 20 minutes or more I get plenty of exercise but not from sport.

I do a fair amount of horse riding, mustling (sic) cattle, I also do a lot of hard work which involves a lot of walking and running.

Two women wrote about efforts to exercise, despite a potential barrier. One woman wrote of her intellectually disabled daughter.

She works at a workshop packaging & walks there & back twenty minutes each way.

My ankle was broken 12 October 1995. In plaster for 2 months, 2 screws. This causes quite a lot of difficulty in our lives including a 10 kg increase in my weight. I walk an hour per day on the beach to improve things.

### ***Reasons for not exercising***

Without explicitly commenting on the benefits of exercise, several women explained why they were unable to exercise as much or as often as they might like. They identified medical reasons such as polio, arthritis (many), adhesions, vertigo, spurs, carpal tunnel syndrome, tennis elbow, Ross River Fever, leg ulcer, accident, pinched/trapped nerve, back surgery, stroke, breast cancer, broken ankle, shin splints, foot problems, back pain. For example:

I had a bout of Ross River Fever and low iron in the last six months of 1995 and I feel I am just recovering from these conditions. Prior to these attacks I attended a gym 3 times a week plus walked for 50 mins 4 - 5 times a week.

I have also had to stop playing squash because of Carpal Tunnel Syndrome, and feel that I am now not doing enough exercise which I know would help my stress levels. I intend to rectify this by starting to walk each day.

For the past 3 months I have suffered a fair bit of pain with a tennis elbow, reach pain, and possibly a damaged nerve in the upper arm (that's where the pain is) which has curtailed my badminton twice a week, line dancing and marching. I feel as though it's a million years since I felt fit and had some fun and recreation.

I have no health problems other than an ulcer on the inside of my right leg I have been on a waiting list for 2 years now to have it operated on without any joy. Because it is open and seeping, my foot swells, aches, etc. constantly. Interferes with activities, and my work. Examples: Restricts exercise, can't swim or go in salt water, can't walk long distances or stand constantly. I also cannot drive for more than an hour at a time as I need to rest my leg off the accelerator pedal as the pain becomes quite intense.

Due to an accident on 27.11.92, I slipped on wet grass and fractured and dislocated my right ankle. I sustained a Pott's fracture and this has given me a lot of trouble since. I now suffer from pain in the hips, lower back, neck, leg and ankle due to my altered gait as my ankle is unable to move freely. I miss being active. (I used to walk regularly for exercise) but now find I can't do this. I have difficulty in standing or sitting for prolonged times.

One woman could find no excuse for not exercising more: '*I should get more exercise but don't and I'm not sure why.*'

Analysis of the quantitative data for this cohort established that women who are carers are least likely of all women in this group to exercise. The responses below provide some insight into the reasons for this association.

Both my younger daughters are multiply disabled. Sleep and back/joint problems stem directly from their care. Lack of exercise is due to time/substitute care problems. One cannot push two wheelchairs!!!

Would love to engage in vigorous exercise (have always done so) - as stress reliever - but no time, no child care.

I am married to a Vietnam Veteran who is now a TPI recipient. He suffers very badly from Post Traumatic Stress Disorder. My 13 year old son has Attention Deficit Disorder. My time is divided between them and my widowed, unwell mother. Working 6 - 8 - 10 hours a week provides an outlet which I very much need, but my innate buoyancy is suffering so I have reduced my days (if not hours) I work to cope with the housework, etc.

Time constraints are also an issue for working women who would like to spend more time exercising.

Just on one year ago I returned to the workforce full time after 16 years "at home". I do enjoy my life but it is very chaotic. The one thing that has suffered is my exercise. I just don't have the time!

If I was able to exercise everyday for half an hour I am sure I would feel better but it is hard to find time as the phone has to be manned at all times.

For instance I work a full week, plus drive approximately 45 mins in peak city traffic each way to work which to me makes a long tiring day.

The problem is that I work so much that I have no time to go to gym.

Tiredness was identified by one woman as a reason for not exercising: *'I find weight loss very hard. I feel exercise would help but I get tired & therefore don't bother'*. However, lack of exercise can actually cause tiredness, because low fitness levels mean women may not have the energy to cope with their everyday tasks. This 'cyclic' relationship between exercise and tiredness was hinted at by one woman, who also suffered from depression.

I am more depressed more often. I worry a lot and often feel too depressed to exercise which has created a vicious cycle where I constantly feel tired and even more depressed.

Embarrassment was also suggested as a reason for not exercising.

Although technically obese my health is good but find myself in a vicious cycle re exercise, ie I'm too ashamed of my weight to do things in public and find the level of activity I used to be able to manage easily (eg 10km or more bush walk in a day) I can no longer do because of my weight.

### *Strategies for increasing exercise*

One or two women offered suggestions which would enable them to exercise more easily, including concession rates for participation in organised activities, improved access to facilities, and having someone to exercise with:

We need activities for health fitness, eg. swimming , aerobics, yoga, walking, bicycle riding, at half price to healthcare holders.

I have put on weight since 1993 - unable to work out like I used to. I was very fit and wore smaller clothes. Unable to run and limited walking - experience pain next day if I exercise out of water. No heated pool in town - only able to use special spa twice a week and that's only during working hours.

My life is much more 'serene' now than it was probably 6-12 years ago! This includes relationship with my husband; work situation; son's drug problems and related activities. I have recently started going to a gym again for aerobics and aquarobics. This is mainly as a support for my daughter-in-law but hopefully I will benefit also!

Another woman raised the issue of work-based exercise programs - particularly for public servants!

I am very disappointed that the Australian Public Service does not provide facilities within the workforce to improve and maintain good health of their employees. My work creates couch potatoes.

### *Conclusion*

Women attribute weight gain to a number of reasons, and many demonstrate an understanding of the health consequences of remaining overweight. Although there were generally positive perceptions of the weight loss industry, there appears to be less help available for the weight problems of rural women, whom the quantitative data show to be heavier than urban women. While the 'beauty myth' appears to be alive and well, there are nevertheless indications of resistance among many women in the middle-aged cohort, with some calling for an acceptance by women of the shape they are.

There were diverse definitions of 'exercise' and many reasons given for not exercising. Women who were carers identified a lack of time and associated problems, such as a lack of substitute care, as significant factors. The quantitative data attest to their disadvantage, showing that women who are carers are the least likely of all women in this group to exercise. Working women also reported a lack of time and also their 'tiredness', indicating perhaps a need for education about the relationship between lack of exercise and tiredness. Suggestions put forward by respondents to enable them to exercise more easily included work based exercise programs, improved access to facilities, and concession rates for participation in organised activities.

It is worth noting here an unintended outcome of the study. Three woman wrote about the effect that actually completing the survey had on them:

Filling in this form has been very helpful in identifying areas of my life that need changing. It has helped me set some personal goals. i.e. lose weight, stop smoking and improve fitness, become less focused on work and work related activities, take up some activities outside home, get some help with work around the home even if I have to pay to do it. See a doctor re tiredness and fatigue and whether some of my symptoms are menopausal.

After filling in this form with mostly negative answers, I'm more determined than ever to change my lifestyle, by exercising, eating healthy food and changing my outlook on life.

I think this was a great survey basically doing it made me take stock and realise that I'm pretty damn healthy and satisfied. Just a lot fatter than fashion permits! Well done

### **2.3.3 VIOLENCE AGAINST WOMEN**

#### *Experiences of violence*

The following discussion explores some Australian women's experiences of violence, looking at factors associated with their experiences and the ways in which they attempt to cope with violence. It incorporates both descriptions of negative experiences and the identification of associated gaps in health service provision and access, as well as reports of positive strategies for managing these experiences.

In response to the open-ended final question, there were fifty-three comments concerning violence from older women and 104 from the middle-aged women. Although this is a small database, it is valuable in providing insight into the ways in which these experiences and their effects are perceived by the women and the kinds of actions taken by women in such situations.

#### *A matter of definition*

Several respondents pointed to the varying ways in which violence may be manifested, emphasising the need for a clear definition of the term.

... mine was not physical but emotional violence.

... effects of being put down during my marriage are long term - it was not a violent marriage but a mentally disturbing one - one where I have been forced to seek counselling. What is the definition of "violent" - is it physical, sexual or mental.

The type of violence most frequently mentioned was that perpetrated by husband or partner, with 54 of the middle-aged women and 35 of the older cohort mentioning such experiences. Factors which many of the women associated with this type of violence included the exacerbating effects of isolation, effects on children including the expression of similar behaviour by sons leading to a cycle of violence, the recurrence of violent behaviour, and the association with cultural factors such as ethnicity or notions of masculinity.

Many women spoke of longer term effects such as a continuing fear of the violent partner, the stresses arising from legal disputes, money worries, the problems associated with being a single parent, disruption to career or the need to re-enter the workforce after a long period, and having to move to another area. While some women noted the creation of barriers to later sexual/companionate relationships, other women spoke of a more recent partner as having been a significant support in overcoming the effects of a previous violent relationship.

Violence experienced by women takes many forms and occurs in geographically, socio-culturally and historically specific circumstances. For example, a difference between the age cohorts in this survey is the association between war service and domestic violence, at least in the minds of the women in the older cohort, whereas partner's unemployment is mentioned by the middle-aged cohort. Alcohol, however, is frequently referred to by both. Although causality or "excuse" for violent behaviour cannot be ascribed to these factors, it is relevant to note the strong association.

A further difference between the two cohorts is the relatively greater sense of autonomy apparently demonstrated by the middle-aged women in removing themselves from a violent relationship. Older women were more likely to have remained with a violent husband or de facto, and not to have remarried until after the first husband died, whereas middle-aged women tended to report that they had left the relationship.

The constraints which kept some women in an unsatisfactory partnership included their perceptions of a need to care for their violent partner or their children's need to have a father. They also said they were hindered by lack of money, lack of accommodation, or the fear of further violence.

### ***Types of violence identified in the qualitative data***

As noted above, the type of violence most frequently reported was perpetrated by a husband or de facto partner. Women in these two cohorts did not use the term "boyfriend", although several spoke about a male "friend" with whom they had had a long term relationship subsequent to the violent partnership.

Other types of violence which were mentioned included the following:

- \* Violence from other male family member(s)
- \* Rape/sexual assault by male non family member(s)
- \* Child sexual abuse
- \* Violence associated with robbery, break-in and/or assault related to theft.
- \* Violence experienced by a family member
- \* Workplace harassment
- \* Violence perpetrated by other women
- \* Abduction/adoption
- \* Other

These categories are, of course, not mutually exclusive, and there is considerable blurring of the boundaries. For example, some of the women who were raped were in their early teenage years at the time, literally between childhood and adult womanhood, and there were mentions of rape in marriage.

#### *Violence from other male family members*

There were a number of responses mentioning fathers, although most of the incidence of this behaviour falls into the category of child sexual abuse. Several women reported violence by their sons, generally bracketed with the violent behaviour of their father.

At times both my son and husband become abusive with their drug and alcohol and psychological problems and often this is directed at me.

#### *Rape/sexual assault by male non family member(s)*

The kinds of rape reported included date rape and 'pack' or 'gang' rape of young women, as well as one case of the rape of an older woman invalid in the course of a house break-in.

The long term effects on her health were detailed by one rape victim.

I suffer from chronic herpes as a result of being raped. Whenever the lesions appear, I become very depressed. I am currently taking Zovirax to keep the herpes away, as it is chronic (occurring twice weekly) without the drug. I have also to take Prothiaden to keep from being depressed. I blame all of this on being raped, and I relive the experience each time I get a herpes attack.

#### *Child sexual abuse*

Approximately one in six of the women who wrote comments reported instances of child sexual abuse, and many noted the long term effects.

History of sexual assault affects the ongoing health of many, many, women, with little or no help given to prevention or counselling to help overcome the ongoing trauma that never dissipates - regardless of the current age of the victim, the trauma and subsequent anger, guilt, betrayal and incredible sense of loss is ever present.

Some women, however, also noted their recovery.

Childhood sexual abuse - 31 years after the abuse ceased - about 39 years since it started and 15 years since my father's death - I can finally say over the last 12 months it no longer causes me the mental and physical problems it did for numerous years. My relationship with my husband of 26 years is terrific and sex life great as I can finally allow myself to be a sexual being.

Although such violence seems to have been carried out predominantly by a male family member there were mentions also of men close to the child such as a neighbour and, in one case, a minister of religion.

### *Violence associated with robbery, break-in and/or assault related to theft.*

Long term residual fear was evident, particularly at night, after a violent attack.

I have circled Yes for being robbed, although it happened nearly 2 years ago, the trauma of it is still with me daily, and I have a great fear of knives, people running and balaclavas, as well as suffering nightmares on an average of once a week. I feel it is still affecting my health and wellbeing.

Fear of attack from strangers appears to be more prevalent amongst older women. Several women commented on not feeling safe at night or not wanting to leave the house at night. Others mentioned that they kept a dog, in some cases for company but in others as protection.

### *Violence visited on other family members.*

For many women, violence against family members, whether it was a daughter's rape by a stranger or violence within the family, appears to have affected their health.

My daughter was raped and stalked frequently 14 months ago. The offender was found not guilty on a "legal technicality". Victims and family members of the victim have little resources to use for support during and after court appearances. Violence to women affects their wellbeing and health and needs positive changes re legal, protective, counselling issues.

When I try to answer the questions about stress, I am not stressed in my relationship with either of my children, but very much the meat in the sandwich between them and their father.

I have had a very unhappy life over the past five years as my husband was charged with sex offences against my young granddaughter. It has made life very hard for me with my family as I am still living under the same roof as him for financial reasons. I am trying very hard to get out of here but at my age it is very difficult, but I hope to be able to do something in the near future. My health did suffer a lot from this trouble but I feel I am stronger now to do something if it is financially possible.

### *Workplace harassment*

It is of interest that there were only a few comments concerning sexual harassment in the workplace. It may be hypothesised that this type of violence is either more prevalent and/or of more concern among younger women rather than middle-aged and older women. However, this comparison is beyond the scope of this report, which discusses only middle-aged and older women.

### *Violence perpetrated by other women*

Last October I was bashed by a drunken woman. It took a long time to recover from that. I still have the inflammation in my arms.

Violent behaviour by female family members was also reported. One woman reported attacks by her ex-husband and his girlfriend, another of being abused by her stepmother. Several mentioned abuse from their mothers:

I also had a rotten drunkard for a mother who made my life a misery and nothing was ever done about her. Now you look at your children the wrong way and you're in trouble.

### *Abduction/adoption*

There was one reference to having been removed as a child from Aboriginal parents, another general reference to having been adopted, and several to having given a child up for adoption. Clearly these are seen by the women reporting the incidents as significantly violent experiences with long term effects.

### *Other*

Other experiences of violence ranged from having been held hostage and having been involved in the Port Arthur massacre, to car accidents and house fires. There were also complaints about exposure to noise pollution and violence in film/media.

### ***Factors associated with experiences of violence***

#### *Alcohol*

The strong association of alcohol with domestic violence and the perception of its causal implication is clearly identified in the comments made by the women surveyed.

During 1948-49-50 my first husband was alcoholic and violent - I left him taking 2 infants away with me - these I raised. After his death in 74 I remarried to my dear husband 1982.

My children and I shared 30 years with a hard working confused extremely violent alcoholic whom we both loved and feared. "John's a good man when he is sober".

I had a very unhappy marriage with an alcoholic, who constantly beat me and my children and tortured me mentally. I divorced him after 37 years of marriage but when he was dying with cancer I had him back and nursed him for 18 months.

Spouse (died 1988) violent last 20 years of his life owing to alcohol and prescribed drugs. Actually, typical paranoid personality. I would never have survived only for my 2 sons.

The comments above illustrate a characteristic of the older cohort. Three of these four women remained in violent relationships for many years. In contrast the middle-aged women quoted below are more likely to have left a violent alcoholic partner.

I have recently separated from my partner who is an alcoholic and I am enjoying some peaceful, quality time finding myself and becoming closer to my children. I am happy being alone by myself as I have a network of friends and colleagues I can turn to if I need them. I must admit that I am somewhat nervous about my future relationship with my ex partner and I have a restraining order on him and I hope that he just gets on with his life and I can get on with mine.

I lived in a violent marriage for 12 years. Alcohol related - and last 12 years being on my own was the best thing for me, I am a new person and I very happy with the person I am and my children grew up to be well adjusted young adults at 25 and 30. They respect me more now than they did when we lived with violence.

I have been in two VERY ABUSIVE marriages caused through alcohol and now am very happy in a non drinking environment.

In 1990 my husband was made redundant. He has never worked since. I supported the family for 4 years whilst he progressively drank more alcohol and became increasingly abusive and violent. In 1995 I finally extricated myself and our children from this marriage. I did not want that marriage to end, but finally had to accept its demise. There is absolutely no chance of reconciliation and of course the children and I are much better off without my husband living with us. He does not see them often (his choice) but they now refer to him affectionately. I am slowly getting my emotional and physical life back in order, and the children are now thriving especially my younger son.

A woman who experienced two violent relationships with alcoholics points out that although there is much more assistance now for women in this situation, the incidence of male violence appears to be as high as ever and is not being given sufficient attention.

I have been married three times. Third marriage has lasted 25 years. Had two children 1st, 4 children 2nd, 7 children to the last. Don't get along with any of my first children. 1st 2nd husband bashed me daily and both were alcoholics. When I was first married there was nothing no help what so ever for battered woman. Now I think it's gone overboard. But more should be done to stop men bashing women.

### *Caring*

There is also an intersection of violence and caring, demonstrating the strength of the caring ethic internalised by many women. For example, the frustrations of men who are ill may be visited on their wives. Some women remain in an unhappy relationship to care for a husband when he becomes ill. An example is the woman quoted above, who took back her violent husband whom she had previously left and cared for him for eighteen months during the terminal stages of his cancer. Other women talk about psychiatric illness, brain damage, etc. It is well recognised that women do the bulk of the caring work in Australia and that most of this work is unpaid and generally undervalued. Coping with violence adds to this burden and to the stresses on women's health.

Three years, Jan 1993, my eldest daughter from a previous marriage left home to work in Queensland. I found that hard to cope with. About 6 mths after that, my husband told he had a terminal illness. I found that hard to cope with. But 2 years ago, my daughter (S), told me my husband had sexually abused her as a child. Major to cope with. There was a lot of help for her but not much for me or my husband. I felt I couldn't leave because of his illness and two other children to care for. My physical and mental health were very low. Our marriage was very unsteady. During this time I met a caring man who gave me support and love and helped me.

### *Isolation*

In many cases women said that the effects of violence were exacerbated when they felt isolated, particularly because family members, especially adult children, were geographically distant as well as because of the area in which they lived.

I was (sexually abused) and it has affected me even into this day. When you live in an isolated area have to rely on others for transport and things are so much harder to overcome.

Several women noted that they had been effectively stranded when denied access to the family car.

I was never allowed to learn to drive so at 72 I took driving lessons, passed my test so that I did not have to depend on strangers for transport.

His threats include - removing parts of the car so I could not drive to town (we live 5 1/2 miles out and our car is the only transport).

### *Effects on children, and the 'cycle of violence'*

An extra stress for women is the effect on their children, and the assistance the children may need.

Husband does not get on with sons - mental abuse major problem. Help not enough when children younger No one would believe me. Has had major affect on 20 year old son.

Furthermore, effects on children are perceived sometimes to give rise to further violence against women from the children themselves.

### *Recurrence of violence*

Some women reported that they had accessed counselling and that this had initially appeared to have made a difference but that their partner had subsequently repeated the violent behaviour.

I will give you a brief account of my experiences of living in a violent relationship for 28 years. I left (husband) twice and came back after a lot of pressure and promises, but nothing had changed

Other women noted that they had had several violent relationships.

### *Long term effects of violence*

As several respondents pointed out, the effects of violence typically endure for some time.

Your questions ask "During the last 12 months ..." The scars of being abused and violated impact on one's life for many years. It has taken 5 years to get to the stage to begin to create a meaningful life and future for myself and my children.

I would like to see more harder punishment for abusive violent partner than a slap on the wrist as the devastation a woman feels, the absolute and total fear she feels, is not only indescribable but is also life long and NEVER forgotten.

### *Legal disputes*

All too often the aftermath of a violent relationship encompasses conflicts concerning rights to property, and/or issues of access and custody of children of the relationship. For many women, the legal system is frightening and bewildering and it almost inevitably represents further emotional and financial stress.

The biggest impact on my health were the injuries and stress caused by a violent and abusive marriage. It took 18 months of legal wrangling to get a property settlement, followed by several years of legal procedure to get child support. Then when the children turned 18 (and were still students) the support stopped so more legal fees and court cases. The cost was thousands of dollars and much stress. (My ex-husband earns \$120,000 ++ 1 year)!

### *Disruption to career/workforce re-entry*

Women re-starting their lives can experience the tensions and pressures of finding a job or undergoing retraining, or getting back onto the 'career ladder', after a long period (which may be up to 25 years) out of the workforce.

Enormous stress during the past 5 years due to the abuse and sheer malevolence of my ex-husband has resulted in cancer, depression, hormonal problems, therapy. During this time I had the added stress of starting work again after 25 years in order to support myself and children (having given up my career 25 years ago to look after my children - as one did in those days).

### *Fear*

One of the most insidious long-term effects of experiences of violence is the residual nervousness - if not fear. This may be accompanied by a lack of self-esteem or self-confidence.

I have had a lot of fear and stress from my ex-husband and the problems he has caused. I believe he will kill me when he gets out of prison. I have been told there is nothing I can do until he tries.

### *Stress of single parenthood*

For women who become sole parents there is the cumulative weight of financial demands, childcare responsibilities, and loneliness, in addition to many of the effects of violence which have already been noted.

In dealing with life after a divorce the main problems are finance, support for self and caring for children, securing for the future which leaves a big black hole. It is a time when women need so much help. Counselling is very expensive and not readily available to help with depression and advice in caring for children who also need special care. I believe councils should look at providing home help, maintenance men - having to maintain a house without carpentry/plumbing knowledge and no finance to pay is frightening. You feel very helpless. The problems of having to provide for children with minimal help from ex spouse is being addressed but it is very easy for men to hide money and it is sometimes just too difficult to pursue. The harassment and emotional trauma involved is very difficult and draining.

### *Barriers to later sexual/companionate relationships*

Experiences of abuse and violence may prejudice the ability of some women to relate to men and preclude them from ever maintaining an intimate relationship. However, several respondents noted that a supportive partner had helped them to cope with the effects of earlier trauma.

Sexual abuse has been a major influence on my mental wellbeing from childhood, and my ability to handle relationships with men.

Still have bad days but try to think positive... and there have been many good things happen. Especially my husband!

### *Moving*

The physical disruption of having to move from an established home or familiar community and settle somewhere else tends to be overlooked. As this respondent notes, becoming a 'displaced person' may be associated with anxiety and depression.

I was married for 20 years, but I left my husband at the beginning of 1995, because of his emotional and verbal abuse and sometimes physical abuse. The trauma of the separation from my husband, of moving interstate and living with my mother and daughter while my son remained at boarding school in another state, caused me much stress and I became depressed and anxious.

### *Physical health*

Several women reported that they had feared for their lives and the homicide statistics in Australia testify to the validity of that fear. More generally however, the physical effects of violence on women's health ranged from acute trauma to chronic disability.

I suffer from chronic Herpes as a result of being raped.

... my sponsor/uncle assaulted me (major assault as culmination of 5 months sexual harassment, propositioning/indecent behaviour by uncle. As a result I have suffered incredible emotional loss, physical disability...

My illness was caused by a violent husband I have been separated from since 1988. My nerves were caused by living under 'protection orders' for 8 years. The stress over money and raising a child alone and the difficulty in finding work at my age all contribute to illness.

### *Mental health*

The nature of the data, in being self-reported and from a small base, means that it is difficult to note anything more than general aspects of the effects of violence on women's mental health. There does however seem to be a suggestion that ongoing problems are more likely among women who have experienced child sexual abuse rather than women from situations of domestic violence.

Many women speak of 'breakdowns' but it is not clear exactly what is meant. The most common symptoms of mental ill health appear to be depression and feelings of isolation and unworthiness. Several women have attempted suicide and there seems to be fairly

widespread use of antidepressants. Episodes of psychiatric treatment, hospitalisation and prolonged psychotherapy were also recorded.

I am on major anti-depressives as a result of ... consequences of domestic violence.

I go into a psychiatric hospital if things get too much.

### ***Violence as a hidden problem***

Despite increasing concern with issues of violence, the responses indicate that violence often remains a hidden problem either because women are unaware of what can be done, or because they are reluctant to admit to their experiences - sometimes even to themselves.

There were a number of comments which indicated that women were very often not aware of resources available to them.

I was molested by my father while in primary school. My father was a nasty drunk. I married another drunk, but he was a happy drunk. I had 3 children, but after about 4 years he got nasty to them and didn't work. I worked full time to support children and husband. My father moved in with us and started the treatment I got from him on my daughters. With support from my doctor and school teachers, etc. I took my children and left. It was had [sic] did not apply for social help, didn't know it was available to me. I met my present de facto, but had a lot of emotional problems allowing him to help us. I tried OD on anti depressants. My kids carted me off to hospital .

More education is required re abuse situations.

Violence which has occurred in the past can have residual effects such as depression, anger, etc, but it was also apparent from some of the comments that not only may the effects of violence be long term, but that they may be masked.

Filling in the survey helped me focus on aspects of my health I had not considered.

Other respondents similarly identified the lack of awareness, and also an unintended outcome of the survey process.

Centacare is marvellous, but sometimes women do not know help is available... Most women are too intimidated to ask for help. The very fact of being able to write it in a survey may prove helpful.

Staying alive has always been difficult for me, and I've never had any help because all the above and more is my secret. This is the first time I've formally admitted it.

A particularly salient example of this 'masking' was revealed in a letter from one respondent, who wrote that she 'gave a wrong answer' in her responses. She had in fact experienced significant violence, including rape, but had been unable to admit to this in filling out the form.

There was a question about forced sex - I answered no as I wanted to minimise the way my first husband treated me for my own mental comfort. Thinking about that time of my life, I forgot the time I was raped when I was 16.

### *Constraints on women experiencing violence*

Several women said that their local doctor was aware of the problem of domestic violence and encouraged them to move out of the relationship. However some of these women perceived that they could not do so for financial reasons, or because they would have nowhere to go, or because it would be 'risky' for them and their children, or even because they are caring for the abusive husband.

As noted above, women in the older group have often remained or still remain in an unsatisfactory relationship for a very long time, up to fifty years, whereas the middle-aged women are more likely to have left that kind of relationship when their children were teenagers if not before. However, many of the problems of the middle-aged cohort remain concerned with domestic violence, in that they are worried about the effects on their children, or about threats or intimidating behaviour from their ex-husband, or the financial problems of being a single-parent and the stresses of re-entering the workforce.

There seems however to be a relatively high frequency of remarriage after an earlier violent marriage, in both groups.

### *Strategies for coping with violence*

#### *Health services*

Counselling is primarily spoken of in general terms, and available resources are seen to cover a spectrum. Among the providers of counselling services mentioned were a Women's Health Centre, a psychologist, psychiatrists, GPs, a Family Court counsellor, Centacare, and specialist social workers. There is much evidence in the women's comments that counselling has made a significant contribution to their ability to cope and recover from experiences of violence.

Dad alcoholic and womaniser, mother puritanical and manipulative. My son abducted by ex-husband when son was 10 yrs, and not seen by me till 14 yrs. All these things and much more helped me on my way to nervous breakdown. Dr put me on HRT and Prozac, once weekly counselling and my life started to have meaning again.

Counselling has a number of dimensions. While some women need personal counselling, they also often seek counselling for others, such as a daughter, and also for the perpetrators of violence, whether it is their partner or another family member.

I was married for 20 years, but I left my husband at the beginning of 1995, because of his emotional and verbal abuse and sometimes physical abuse... The stress of finding work again in a new place and being a single supporting mother for the first time also caused me to feel anxious and to lack motivation. However, after much negotiation with my husband (he agreed to go to a men's counselling group and also counselling sessions with me) we decided to have a reconciliation. I returned at the beginning of this year, 1996. I stopped the medication last November and looked forward to a fresh start. Since the beginning of April this year my husband and I have been overseas on an educational tour.

Things went really wrong when waiting for a permanent visa (1994). We got it now (1995) but for almost 2 years my husband could not handle the stress of just waiting for that visa. Well, his job was good but he took it out on us. I should've asked for help much earlier. My GP helped me well. Emotionally I was broken. He gave me a letter

for immediately counselling... In that same week things went bad again. I told him I saw our GP and I will go to counselling and luckily he came along. Things went better for a little while; but this year he started behaving badly again. This time I left (domestic violence). He still wants us back but I told the Family Court Counsellor that he needs to learn how to control his temper and frustration. They fully understood. We came here to Australia for 3 years on a temporary visa. We are here on our own. But I have some good friends to talk and to help me out.

Issues of mental health need to be addressed. For many years I had extreme behavioural problems with a child. Many situations were extremely violent and difficult to handle. During these years I spoke to several GPs and school psychologist and a C.S.V. representative. The C.S.V. gentleman I was supposed to see stood me up on two occasions so I spoke with a stand-in, a counsellor with no qualifications. He tried to offer advice, chiefly, regain power and kick the boy out. The boy needed help. He finally got it after nearly killing himself and smashing up the family car in the process. He saw a fine psychologist, etc. He has been diagnosed with a personality disorder, is off drugs and is no longer physically violent. He is still unemployed, however.

A migrant who was able to access counselling wrote of her experience of an assault by the uncle who had sponsored her. She notes the importance of the counsellor's assistance in dealing with the practicalities of her material situation.

... major assault as culmination of 5 months sexual harassment, propositioning /indecent behaviour by uncle. As a result I have suffered incredible emotional loss, physical disability and financial ruin (no law seems to apply - If I had arrived now - he WOULD be financially responsible for me. Counsellor has been a real help in dealing with all this - I am just devastated and scared to death.

Nevertheless there is obviously a need for greater service provision, given that many women had not accessed counselling and there were a number of comments indicating that resources were not available.

Counselling is very expensive and not readily available to help with depression and advice in caring for children who also need special care.

There were two specific mentions of areas which lack adequate counselling services. One is of interest not only for the report of the apparent inadequacy of its resources but also for the identification of negative community attitudes.

The area of (district X) desperately needs a counsellor for victims of domestic violence. The lady who is currently the DV Worker is only capable of "referring people", but is not able to counsel the victims on a weekly basis nor able to set up a support group. The previous DV worker had all the skills needed, but the "group" who now run the "Community Centre" at (suburb Y) are too frightened to have this sort of group in their centre. They want only "nice" things happening in their area. (District X) has the highest rate of domestic violence in the State of NSW. I help these ladies as much as I can, but they desperately need a trained counsellor in this area. Where do you start to get assistance for these women when no-one wants to know or get involved.

Another respondent from a remote area noted the lack of services in her district. This woman, whose daughter was stalked and raped, wrote:

The local female counsellor for a huge district provided whatever time she could but had no assistance herself and follow-up was non-existent.

It is possible that these comments reflect a wider situation, rather than isolated deficiencies in service provision.

### *Friendship networks and family support*

The conventional wisdom that women use informal avenues of support was borne out by the comments from many respondents who said that it was their family and/or their friends who helped them cope.

### *Legal provisions*

The responses indicate that women do access legal provisions,.

The last twelve months have been difficult for me for various reasons, eg. ending a relationship due to infidelity, commencing a court case of sexual harassment against an ex-employer.

I have been in a violent marriage for years and have had two breakdowns and was in the base hospital special ward. Then in March 1961 I had him charged with assault and things were much better after that.

Nevertheless, women still appear to be disadvantaged financially when they end a violent relationship. As one respondent commented:

It is very easy for men to hide money and it is sometimes just too difficult to pursue.

Another pointed to ways in which financial resources were 'hidden'.

Then he wanted a divorce to marry another woman. I told him he could pay for it. He got the divorce in Adelaide and told them we could not agree and we were living apart for 12 months. We had to sell our home and I got half the money which was \$40 thousand. He had a Statesman Holden car and thousand of dollars he had been coins collected over the years, and also a lot of electrical tools. I got no part of them. He had also bought a house in Adelaide.

It appears however that the middle-aged cohort are more likely to seek legal solutions than the older women. This is consistent with the seemingly greater ability of middle-aged women to leave a violent relationship. One woman who did take positive steps has found wider benefits of such assertiveness.

Yet despite all of this I have never felt more satisfied with my general situation at any stage of my life so far, nor have I felt more confident in who I am. I have in fact learnt to like myself - warts and all.

### *Medical treatment/drugs*

A rape victim attributes her coping with the event to successful medical treatment.

Thus, while I feel fine now, and I am in good health mentally and physically, this would not be the case without the (prescription) drugs I take - and have done for many years.

I am slowly getting my emotional and physical life back in order, and the children are now thriving especially my younger son. I decided not to let bitterness and anger dominate my new life, and for the most part am optimistic - or try very hard to be! I have just finished a 6 month course of anti depressants.

### *Separation from partner*

As noted previously, women appear to be more able now to move out of a violent relationship than they did in the past. The emphasis, however, is on their removing themselves from the situation. Attention perhaps needs to be given to the removal of abusive partners, rather than the dislocating of women and children.

### *Other strategies*

Other strategies to combat violence or its effects ranged from having guard dogs to changing the direction of one's career. A number of women mentioned that they had returned to study.

Got my Grad Dip Ed at age 48.

When I started back into the workforce (1989) I was able to partake in "Retraining Office Skills" at TAFE. It covered wordprocessing accounting, personal skills and self esteem etc. It was a wonderful course and of the 10 participants 7 are still employed and moving ahead with their lives. This course was discontinued. I would think at great expense to the public.

### *Conclusion*

While many women reported seeking help, there were a number of women who made comments such as, 'I cope':

Necessity is a great teacher and I gained the strength to cope.

I'd like to clarify that I was in a violent relationship and yet claim to be satisfied with my past partner. I was satisfied with my input in controlling that situation and what I made of him during the marriage.

I don't worry the doctor because I COPE. (emphasis in original)

I cope fairly well, I think.

Date-raped once 35 years ago... No bitterness or recrimination.

The comments above suggest that a fruitful area for research may be to look at the strategies used by women who make such comments. In most cases the brevity of the comments do not allow for further analysis although one woman who felt the constraints of the traditions of her Italian heritage, including an arranged marriage in her teens, noted that she had coped with a violent husband and her later separation from him with the support of her family. She did remark, however, that she felt she was “a strong person”.

I feel that I've always been lucky to have a great attitude towards life that keeps me going. With the help of good friends and loving sisters, I feel that a lot of unhappy things that have happened to me attributes to my health problems as well. I feel that as a woman from an Italian background I had to stay in an unhappy marriage, and still get bad vibes after 12 years divorce. Even my own sons have their father's attitude towards me. It doesn't seem to matter how much I've lost, worked, or been sick, even in this day and age. I'm a woman and should put up with it, and sometimes I feel that I do too, I feel that I am a strong person.

### **2.3.4 LIFE STAGES AND KEY EVENTS**

The comments made by the widowed women in the 70-74 age cohort provide an extensive commentary on the nature of widowhood. The women's responses underline the strong desire of older widowed women to express their needs and concerns. Preliminary analysis of the qualitative data reveal a number of major themes.

#### ***Adjustment to widowhood***

Widowhood is obviously a period of great adjustment and time is an important part of the healing process. While even women widowed for many years explain they “never get over it” there is a strong sense of “survival” and independence expressed in the women's comments.

I cried most days for about 12 months. Some days I still feel sad I suppose that is because we did everything together and never made any decisions without each others consent.

It has taken me quite some time to adjust, as we were very happy together.

I have managed to survive and lead a comfortable and quite interesting (albeit at times a rather lonely) life. I am pleased that I have moved, settled and adjusted, and handle all my affairs. I shall never get over my loss but I have lived to see the day!

Many women find themselves alone for the first time in their lives and find they need to develop independence and self-reliance.

It is a big adjustment to living alone again

My partner of 30 years standing died two months ago and I now must adjust to living without the help and support he gave,

Since the death of my husband, five years ago, I am living alone for the first time in my life..

Being a widow of 18 years with no children, I have had to become very independent.

Many long-term widows describe their experiences of widowhood in light of their married lives - some are relieved of the role of carer and husband, often described as a very difficult period.

At seventy years of age I look back on a period of my life - aged 30 to 40 when it was a particularly stressful time- nursing a young husband who died age 36 - at a time when there was no social help at all - one wept in one's bedroom at night and got on with life and yet I believe it made me a stronger person and a well adjusted aged women, as I feel I am today.

### *Attitude*

Throughout the comments there is an attitude of courage, strength and stoicism. Many women talk about accepting their lives, use humour as a coping mechanism, and give the impression of being tough survivors of major life events (many have experienced the death of parents, partners, children and friends).

I never feel sorry for myself and have always had courage regarding deaths in family and never allow myself to be disgruntled and always feel bright.

Today I enjoy my little corner of content. Thanks to life's ups and downs I value each day. Life's trifles don't upset me. I look forward to a reasonably healthy happy life at 90.

Necessity is a great teacher and I gained the strength needed to cope.

Life wasn't meant to be easy but I find it interesting, challenging and surprising and worth living a day at a time.

"Grief or pain lasts for a night but Joy cometh in the morning" (if I'm not taking Sinequan???) I am blessed with commonsense and a sense of humour.

Some express dissatisfaction with their lives but the majority display a lot of courage, which they equate with who they are - their identities. They all yearn for ongoing independence, but often have to face the impact of poor health or ageing on their freedom.

Perhaps the ultimate stories of women's strength and capacity are provided by rural woman who carry on their farms despite their single status, and their age.

I have been canefarming since 1964 and continued on after my husband passed away on 6/7/77 and have built the farm to double its size. I have always done the rotary-hoeing on the fallow fields even when my husband was alive. Last year I did 51 acres as well as assist to load the sugar cane onto trailers - cart it and once planted always 'run the drills'. Also disced fields and ripped some sections on a large 4440 John Deere tractor - and I enjoy every moment - 31 acres to do this year. So - you can see that my health is fantastic. Drs wouldn't have a job if all people were like me!!!

I am widowed and manage and run my farm alone which at times is difficult with changing seasons not being favourable. I find that I am frequently requiring medical dressings to cuts and abrasions sustained during daily chores about the farm. It is my choice to remain on the property as long as my health and finances allow me.

### ***Health Issues***

The health effects of loss of spouse and living alone were also of concern for some women. For recently widowed women, stress and grief-related problems underlie their major health concerns. These manifest as insomnia, depression and increased anxiety. Women widowed for longer than two years say it can take up to five years to come to terms with the loss of their husband or that “you never get over it”.

From June 1995 to Feb 1996 I suffered severe depression after the death of my husband Dec 1994. I was hospitalised twice during that period. After trying various antidepressants I was given ECT and started to improve very quickly I had 4 treatments I am now very well and attend my local doctor monthly. I had experienced similar bouts of depression - although not so severe - in 1975 and 1990. I was treated with medication only on those occasions.

Insomnia is attributed not only to grief and loss, but also to the alien experience of being alone, particularly at night.

I am coping better now but found it difficult to cope with being on my own at night.

For some women the nights are also haunted by memories and remorse.

My husband passed away 5 years ago and I think of him every night so do not sleep, it's a big problem to me because I think (could I have done anything for him). He died whilst talking to a friend at our kitchen table and I'll never forget it.

In the quantitative data, the significance of sleep disturbance as a problem for recently widowed women is demonstrated by the high prevalence of use of ‘drugs to help you sleep’.

### ***Loneliness and isolation***

Themes of loneliness and isolation flavoured many of the comments.

...naturally my problem is mainly loneliness. I do not put myself on to people. I would hate to be a nuisance to anyone.

I get very cold and lonely at times and miss not having support and encouragement when flagging.

The hardest thing to come to terms with is being alone for the first time in my life. My husband was on the same wave length as me and even with the onset of Alzheimers, we managed to enjoy each others company - always with the identical sense of humour which helped, especially in the latter years.

Remarriage is not a common option among widows: “*I don’t look forward to looking after another man*”. Rather, companionship is sought through friends, with a preference for female friendships. Isolation and loneliness are also recognised pitfalls that are combated through church and community activities, volunteer work and learning to identify with a community family.

### ***Social support and community activities***

Social relationships and the need for intimacy are extremely important to women who are renegotiating their lives after the death of a partner.

Not exactly the best of years but I live in a close knit rural area and the support of family and friends (particularly church friends) has been absolutely wonderful!

My wonderful husband died suddenly 17 years ago and I felt my life was over, but with the love and understanding of my beautiful family and friends I have made a new life for myself by helping those less fortunate than myself and helping my family with their children.

However, many widows appear to withdraw from society in the period immediately following their husband’s death.

When I lost my husband - he was 58 and I 53, nearly 22 years ago now, I was ill with grief, just spent time crying, praying, suicidal, smoking - and a good friend said to me, "Work is the solution. Find all the voluntary work you can and work hard at it". I did this and she was right. I spent my time: helping family first, then volunteer with St John Ambulance (19 years); meals on wheels (cooking, delivering, committee), raising money for a residence for elderly people - too frail to live alone. I was also their secretary - retired from there now. Part time catering job - It saved my sanity. I did not have time to brood anymore.

I nursed my husband for 2 years before he died and I missed him a lot and my daughter joined me in the Senior Citizens and Arts and Craft and that helped me so much.

This need to keep active and engaged in community activities was a key theme in many of the comments.

My husband died nearly two years ago so my lifestyle has changed. I cope by being very busy in the community ie. I am president of two organisations and I still do some relief teaching I sew and paint. I have very little spare time!

I am a 70 yr old widow. Receiving a veteran affairs pension, my late husband was in the navy in WWII. I am healthy and lead a busy life. Live on my own but close to family who are very good. I do some voluntary work (meals on wheels and ironing to St V de Paul shop, go to craft mornings etc). Have been to two computer classes for the over 60s run by the Regional Health Authority. I play indoor bowls and get around in my own car. Had a happy marriage for nearly 40 years to my one and only husband.

The activities that widowed women become involved in often revolve around an established community - the church, clubs and organisations such as Probus and Legacy. These organisations are designed specifically for this generation - there does not seem to be a great deal of intergenerational interaction. Time use also takes on a new meaning in widowhood - staving off loneliness and keeping busy are two major preoccupations for these women.

### *Structural and financial issues*

Widowed women express enormous and ongoing anxiety about financial problems. Often they do not have the experience of handling family or even personal finances as their husbands held these responsibilities. Thus, many are concerned to get adequate information and assistance with finances.

I had not banked, shopped or driven the car for many years and had to learn the lot and each and all helped me. I am still nervous of it all but managing

My husband died after a major operation in 1971 and I had to carry on working the property and pay all the Estate Duties with only partial help.

Many long-term widows talk about living with a husband's debt or coping with a life above/below the poverty line. The upshot of this circumstance on their health and wellbeing is that, in several cases, they drop private health insurance.

My husband left nothing but debts (unknown to me, he had been gambling heavily - and his superannuation had been used up consequently). I can't afford help in the house cleaning department.

I am a war widow so Veterans' Affairs pays for all my Dr's fees etc. I have dropped my private health cover this year. Hope it was wise to do so.

My life was reversed so far as money was concerned and only for the help of my daughter and her husband I would have to be renting. It was a great shock but I realised life goes on and who cares if you became nervous and refrain from mixing with friends and become morose so I have made the best of it all. Many times I feel I will never get in front of it all and after the comfortable lifestyle I was used to I have found it very hard to exist on the O.A.P.

A single pension is obviously more difficult to manage a home and aging car (essential in this locality - shops etc) than a couple - alike; with a lower pension each. I refer to electricity accounts, heating in winter, house insurance, telephone, car registration/insurance/petrol, if outings are together, council rates, even if paid in instalments, or in full, are just some obvious examples! These would normally be shared equally. Other personal needs, .. clothing (often 2nd hand, shops) and personal hygiene - mostly take up any remainder of the pension. Senior citizen groups make up our own cheapest entertainments, concerts etc.

Widowed pensioners find living expenses cause much distress after funeral etc expenses - use up remaining savings rapidly!!

Most 'pensioners' (except politicians) have lived through long difficult times - child rearing up, during the Depression, War service etc. - so would not have much to fall back on now.

Single women, years ago then were low paid workers. I received 10/- (one dollar) ten shillings (weekly) as a 16 year old nurses' aide - exploited and no saving possible then.

Single pensions need to be at least 3/4 of the double one - to 'catch' up and ease financial strains alone.

There is also a need expressed by long-term widows for help with house maintenance - physical work that must be done to maintain an independent life in one's own home. This then raises the issue of housing and the pressure to leave one's own home for a less demanding but also a less independent environment and lifestyle.

Elderly, single women, especially - have great problems - re - home maintenance, repairs, painting etc. We don't usually have the skills, tools or physical strengths to manage these jobs. eg electrical repairs are expensive as well as illegal!! we should not have such unnecessary problems or dangers.

So far I've managed to keep the garden tidy and the house also. My worries are when I need a plumber or painter or carpenter, I have to pay for help and that is my worry. I only had 1 daughter and she has children and house to look, care for and she works, but she does call to see me. Thank goodness. People will say to me, "sell up and go into a unit" but they cost more than I would get for the house so that's out of the question. My opinion is that perhaps we live too long.

Widowed two years ago, I am finding the house and garden too much to manage. That's what worries me most - trying to do all the housework and the garden, and knowing I can't do it - even though I'm very healthy for my age. My children all live in other cities the nearest being 3 hours away - and I have no immediate family living near me. So being alone worries me at times.

I sold my home... 3 years ago as the garden, yard etc was getting too much for me to handle alone, living there 6 years after my husband died.

Travelling long distances with limited mobility or finances can also be a cause for increased anxiety, loneliness and isolation for widows who do not drive.

### *Services*

The support provided by Veterans' Affairs and Legacy was identified as fundamental. As less women become eligible for these schemes, the unmet needs of older women who are widows will increase.

Legacy very supportive

I am very thankful for the help of Veteran Affairs and my doctors who make my life bearable.

The role of doctors in helping women cope with both loss, and their circumstances as widows, is recognised to be of great importance. However, although generally caring, doctors may not offer enough practical support for women.

I have a very caring, wonderful doctor (country GP) who never seems to be in a hurry and a country hospital with a marvellous, caring staff. It would be an absolute disaster if it were ever to be closed as is happening to so many now.

My husband died in July '92, after 48 years of a good marriage. I felt desolate and despairing. The medical profession were helpful generally speaking - they didn't solve the problems that arose. The organisation 'Solace' helpful.

Some women highlighted the need for other counselling services for widowed women.

Perhaps some PRE - death advice could be available to help prepare people. In this small country town, people have been wonderful to me. Church, health centre and Legacy also helpful. But nothing prepared me for the extent of the devastation I have felt. There is nothing so final as sudden death. The practical aspects are well covered by information available. The personal loss and loneliness are perhaps areas where pre-event education could help us before we have everything else to cope with. Just an idea.

I am concerned with the insecurity felt by women left widowed and the lack of preparation for this eventuality. I would like to see more assistance available for women living alone especially in country areas.

### ***Conclusion***

The comments made by widows provide insight into some of the needs and difficulties for widowed women. These needs clearly extend beyond any time limited period of grief and encompass health, social and financial aspects - not just emotional distress. Further analyses of the qualitative data are being undertaken by Susan Feldman (Alma Unit on Women and Ageing, University of Melbourne) in collaboration with Julie Byles (Research Institute for Gender and Health, University of Newcastle). These analyses will contrast the comments of women widowed within two years of completing the survey, and those widowed for longer, and will also contrast the needs and concerns expressed by women living in urban, rural and remote areas across Australia. Further research is planned to provide greater information for policy and services for older women who are widows.

The results of this survey will no doubt look very good when published in the newspapers. Reading back through my own answers I appear to be doing very well for my age and so will many others in my age group 70-74. We are mostly a tough, resilient group, having lived through the depression years in our childhood, World War 11 (with its worries and limitations), and our battles to make homes, work hard and raise families over the years. Many of us married ex-service men whose health was not always good. Now so many of us are widowed and no longer, or do not drive cars, are finding it very difficult living in the country. My town like so many other small towns are without public transport. If it wasn't for my Legacy man and his caring wife I would be in trouble. I am also lucky in that we have a shire community car which takes us to specialists, dentists etc. Veteran Affairs pays for my trips. Our hospital recently closed its doors to in-patients. The one ambulance is overworked, one elderly lady left on the footpath in pain for ages. Two of the three banks recently closed, the remaining one has restricted hours. Modern medicine is wonderful in prolonging our lives, but we still have battles with which to contend. Is anyone listening?

### 2.3.5 USE OF AND SATISFACTION WITH HEALTH CARE SERVICES

There were 1400 comments made by older and middle-aged survey respondents on aspects of health services in Australia. Four areas were targeted for analysis in this report:

- 1 women doctors;
- 2 women's access to health services;
- 3 issues of healthcare costs relevant to women;
- 4 health care services and the emotional and mental health of middle-aged women.

#### (i) Women doctors

##### *Demand for female GPs*

It appears that there is a significant demand among women to be treated by women general practitioners.

The quantitative data show that between 40 per cent and 50 per cent of women in the middle-aged cohort would prefer to attend a woman doctor at least some of the time. The percentage is greatest in urban areas, and least in remote areas. Older women are less likely than middle-aged women to prefer a woman doctor. However, the change in preferences may be related to age, or may reflect generational trends, as the quantitative data for the youngest cohort (aged 18-22) show that younger women are the most likely of all three groups to prefer to see a female rather than a male doctor. For example, 46.3 per cent of young urban women said that they would prefer to see a woman doctor for certain things, compared with 30.6 per cent of middle-aged urban women and 22.1 per cent of older urban women. The longitudinal nature of the study will reveal whether this is a generational difference, in which case the preference will therefore persist or increase, or a characteristic of age, in that women may become less concerned whether their doctor is male or female as they grow older. This may occur if women become 'desensitised' or if their problems become less gendered. An associated variable is the greater presence of women in the medical profession, as preference for care by a woman doctor may relate to past experience and expectations.

**Table 2.2 Preferences for attending a woman doctor, by cohort and area**

Preferences for attending a woman doctor						
	Middle cohort (%)			Older cohort (%)		
	Urban	Rural	Remote	Urban	Rural	Remote
Always	17.2	13.9	11.9	11.3	8.1	6.4
For certain things	30.6	27.7	32.1	22.1	20.0	21.6
No	15.9	18.1	14.6	19.0	19.3	15.9
Don't care	36.3	40.3	41.4	47.7	52.6	56.1

The responses from the two older cohorts concerning health services, comprising seven hundred and fifty-seven comments from older women and 643 from middle-aged

women, were examined in an attempt to shed some light on the nature of the desire for female practitioners.

### ***Problems of access to women GPs***

Although there is a strong demand for women GPs there was also criticism in the responses from the women surveyed that women doctors are difficult to find, particularly outside urban areas, and that they tend not to stay in a practice for as long as male doctors.

I prefer seeing female doctors but unfortunately in rural areas we tend not to get a choice.

Female doctors are in high demand with long wait lists & are not easily accessible

Although I prefer to consult a female GP, there seem to be very few - and they mostly work part time so availability is a problem. At present, I do not have a regular GP I trust (or see regularly) and this concerns me. A medical centre staffed by female GPs only might be a solution?

I used to prefer female doctors as they seemed to listen more, but I've had two females give up to have babies so am going to a male doctor now to try to ensure continuity (I would prefer to attend Out-Patients).

Please can you recommend a book I can read on menopause. I really don't know if it is normal the way I feel. My GP had a lady doctor at his surgery which was great but she left to have a child and isn't returning. I don't feel comfortable talking to a male GP.

I tried to get an appointment with the only female doctor at our clinic - she only works part-time - so after two postponements (once I couldn't go and once the doctor was ill) I saw a male doctor. I wasn't very impressed as I felt he didn't really listen in regard to chemical treatment (Hormone Replacement Therapy).

I think there should be more female doctors. I've had enough of male doctors. They just don't fully understand the female body. I am sick of being brushed off as wasting their time. I now see a very good female doctor, unfortunately her working visa runs out very soon.

I can't seem to find a lady doctor. The only one I know takes a couple of weeks to make an appointment.

To a great extent these factors are explained by the gendered nature of work in our society, ie., women in general do more part-time work, are more likely to be employees rather than employers, do the greater share of childcare and domestic labour, and are more likely to move for their partner's career.

I am 49 years old experiencing the menopause and I feel that maybe this note just may fall on listening ears. I have been to GP doctors who do not have knowledge of menopause. All men. Trying to get to see a lady doctor is not easy for day working women. They all work only office hours.

With my health care I wish the one female doctor was still in the practice (she left because of her husband's work). When I said this to the head doctor he said he found it difficult to obtain a female replacement

### ***Reasons for preferring a woman doctor***

The qualitative data showed that women doctors were often perceived as being more caring, more prepared to take time over a consultation, more prepared to listen, and more empathic. Some of the women surveyed have only recently consulted a female doctor and apparently regret that this had not happened earlier.

I have attended a female doctor in the last few months who is delightful - Wish I had seen a lady doctor years ago - far more helpful than a lifetime of male doctor relationships. Will encourage my daughters to seek out female doctors.

Have recently swapped from male doctor (who retired) after 30 years of being his patient. I was very happy with him and saw other male doctors always. Since his retirement I have seen three different female doctors (both home and work location) - I will NEVER go back to a male doctor again unless situation is urgent. I have found the three doctors to be much more caring, and understanding, breast examination, etc on first consultation. Where have they been all my life!!

However, it is the nature of the way in which women practice medicine, compared to the way in which a majority of male GPs practice, which women find attractive.

If I see my female GP, she takes more time than male GP. Female GP seems to have more interest and understanding of female issues.

The female doctors I have seen have taken more time in questioning me, examination, and discussion of possible treatment.

As well as a 'pull' factor which draws women to the interpersonal skills of female practitioners, there also appears to be a 'push' factor which deters women from consulting male GPs about certain matters, although this may be a matter of comfort and dignity, rather than technical expertise.

Excellent service from our family doctor. I am considering referring to a lady doctor for smear tests or if I need advice for any women's problems that may arise.

Living within a country region - I feel as many of my friends that the provision of more female doctors would definitely be advantageous to the area - especially with regard to female medical problems of menopause, etc. I personally have had to change doctors until finally consulting a gynaecologist in Nowra before achieving understanding and remedy for my symptoms. This has taken a course of almost 3 years of perseverance and finally desperation

Normally any doctor will do, but for gynaecological needs a female doctor is preferred.

For years (ie, always), I have had a male doctor and have always been satisfied unless he was a bad doctor. However, as I approach menopause and sought some support and advice, I was met with a brick wall. Hence I have recently changed to another practice with a full-time lady doctor and now see her when I can and specifically for "female" complaints.

A further dimension of women's preferences is the suggestion that older women prefer older women health practitioners:

I have migraines once a month. I know I am going through menopause - why can't there be more holiness for women like me, sometime I don't know if what I am going through

is normal or is just how I feel or my body is normal and that every women goes through the same thing. I know there are books but talking it through with an expert or friendly voice would be nice. Doctors can be nice but most are *male or young female* and (have) very little time to share. [emphasis added]

Am impressed with the level of health services available in this area. It is wonderful to be able to talk to trained people in an informal environment (Women's Health Centre) rather than a GP in relation to menopause, etc. Some of the emotional changes can be difficult to deal with, and it is reassuring to discuss these with other women *your own age*. [emphasis added]

While most reports of women GPs were supportive, there were one or two criticisms of women doctors among the survey respondents.

The ectopic pregnancy I referred to earlier was actually a foetus attached to the colon. When the foetus aborted at 4-5 weeks I had severe haemorrhaging for 5 days until finally diagnosed by a doctor. I was not at all happy with my local GP who initially diagnosed my severe pains in the stomach as a tummy bug and told me to go home and not eat for a few days. When my husband rang her surgery two nights later (because I was in considerable pain) the doctor said she didn't do night visits. At no time did she ask me or my husband any questions related to possible gynaecological complications. I felt at the time that she was very negligent and have not gone back to her since. It is the only instance I have regarded a doctor as being grossly negligent.

### ***Screening***

There is a suggestion that the ability to consult a woman may be associated with better health outcomes, in that women will be less reluctant to undergo regular screening procedures if they have access to a woman doctor.

Every woman I have spoken to hates having Pap smears. How can this be made more pleasant! Clinics with female doctors?? We have detected many early cases of breast cancer since opening a mammogram clinic here. The staff are delightful-

I live in a rural community and the female doctor I used to see has moved away (about 2 years ago), so I have not yet established another GP.

I have not had a pap test in over two years because there are no female doctors in our small town, and to expose myself to a male doctor is impossible for me. Fortunately the technician who does the mammogram is female.

## *Women's health centres*

References to women's health centres were always positive, and there appears to be a strong demand for such services particularly in relation to menopause. The association between menopause and the desire to consult a female doctor seems to be quite strong.

Please note that in my area (named) we do not have a women's health centre or a community health centre. It is my belief that women in this area would welcome with open arms such a centre.

The obstetrician I saw put me on HRT. This is all for the hot flushes, sweats, and no sleeping - It making it very hard to work efficiently with no sleep every night. The HRT does not fix the insomnia, sweats or flushes. It is very difficult and there is no WOMEN'S HEALTH CLINIC AVAILABLE TO GO TO. IF THERE IS IT IS SURELY NOT ADVERTISED. [emphasis in original]

However, the issue of women GPs is not solely related to menopause. As noted above, the quantitative data from the younger cohort demonstrated that younger women were even more likely than middle-aged women to prefer a female GP. It would seem that menopause, and particularly the issue of HRT, may be a pivotal sensitising experience for the generation of women who are now middle-aged.

## *Conclusion*

There is a significant demand for female doctors, particularly general practitioners, but this demand appears to be driven by a combination of push and pull factors. On one hand there is a demand for the kind of medical practice demonstrated by female GPs, while on the other there is a resistance to consult male GPs for certain kinds of problems. There is some suggestion that addressing the scarcity of women doctors may affect health outcomes, in that women will be less reluctant to access medical services such as screening if they can see a woman doctor.

One woman summed up the reality of the situation which presently applies, ie that although expediency may determine which doctor a woman sees, she nevertheless may prefer a different doctor.

Also the (question) with 'don't care'. Big difference between don't care and don't mind. I am not bothered by a male doctor, but do care.

### **(ii) Access to health services, with particular reference to rural women**

Access to health services is of significant concern to women, and in particular to those living outside urban areas. These concerns are partly related to their own needs, particularly for screening, but also to their responsibilities as carers for people who need medical or hospital services. There is also often, inevitably, a nexus between access and cost.

The problems which rural women have in accessing health services are to some extent shared by men. However, women are greater users of the health care system as both patients and carers and therefore also experience more disadvantage in barriers to access.

## *Women as patients*

### *Access to screening services*

Women are being encouraged to undergo regular screening for breast and cervical cancer, yet they often find it immensely difficult to access relevant screening services.

I think more service mammograms could be better provided for we country women. As in my case a 2 hr drive either way and maybe only one half to three quarter hour visit to clinic.

A mammogram is only available in Darwin - Get one when you are out on leave. The Govt travel scheme does not cover women for mammograms. If you have a lump in the breast, and are not happy to "wait and see" or have it taken out here - whether necessary or not - you pay your own way out. As a woman with a history of breast lumps and family history loaded with cancer, I am not happy with the service provided to women in remote areas. If I have a lump now I fly out and don't even visit a doctor here - very expensive.

I was lucky in that my GP here used to do breast checks 6 monthly and taught me self examination which was how I detected the lump after I went to live in New Zealand. However, I had to travel over 200km to the nearest large city for the mammogram and fine needle biopsy (luckily benign).

Women's - and men's health could be better accommodated in rural areas with the availability of qualified medical professionals who'd be prepared to travel to isolated areas and conduct clinics. Perhaps the facilities of country hospitals could be utilised, publicity given and the doors thrown open for women, for instance, to present themselves for pap smears, bust examinations and any other associated queries attended to. Lengthy trips to large centres for medical appointments cost in planning, travel, accommodation, etc. Preventative health measures should be made accessible on a regular basis to rural Australians.

The interrelationship of access and cost in healthcare is demonstrated in the demand for free mammograms (as early as 30) and pap smears. Some of these comments indicate that women need more information about why current guidelines suggest mammography for women over 50.

When I was 41, I was rejected to have a mammogram by a nurse in the mobile unit. I was told I have to wait till 45 before I could have a free mammogram. Where is the government's health promotion policy? Isn't it better to have an early detection rather than too late?

I would like to see the breast mammogram open to women at the age of thirties and forties then into their fifties. I think for this age group there is nothing in place for them today. If you are going to deal with women's health this one area could be opened up.

I also feel free mammograms should be available for women from the age of thirty or even less if they have a history of breast cancer in the family.

A comparison of the quantitative data concerning the frequency of mammograms and pap tests shows that women outside the urban areas are less likely to have ever had a mammogram than their city peers. This suggests that rural women are disadvantaged when specialist technology is required.

*Access to specialists in rural areas*

The maldistribution of general practitioners in Australia has received significant attention and has already been noted in this report in the context of the restricted options for women wishing to consult a female GP. However, the need for specialist services presents further problems.

Living 4 hours from Brisbane, I find it tiring and expensive having to travel to Brisbane with my disability. I am due to visit the mammogram clinic but it is 107km away and still have [keep] 3 specialists appointments in Brisbane in the next two weeks, so it has to be put off due to expense and tiredness.

The quantitative data show that the frequency of specialist visits declines with an increase in distance from an urban centre.

**Table 2.3 Frequency of visits to specialists by age and area**

Frequency of visits to a specialist doctor in the last twelve months						
	Middle-aged cohort (%)			Older cohort (%)		
	Urban	Rural	Remote	Urban	Rural	Remote
None	52.6	59.7	64.4	41.9	49.8	56.3
Once or twice	29.4	26.9	25.1	30.5	29.0	26.5
Three, four times	10.0	7.8	7.1	16.0	13.2	11.5
Five, six times	3.5	2.6	1.8	6.3	4.5	3.9
Seven or more	4.5	3.0	1.7	5.4	3.6	1.8

It also reveals that country women are more likely to undergo major surgery, such as hysterectomy (see table below), and it may be hypothesised that a radical alternative is the preferred option when compared to repeated visits to a distant specialist.

**Table 2.4 Experience of hysterectomy by age and area**

Experience of hysterectomy						
	Middle-aged cohort			Older cohort		
	Urban	Rural	Remote	Urban	Rural	Remote
Yes	21.1	23.6	26.8	34.5	35.1	32.8
No	78.9	76.4	73.2	65.5	64.9	67.2

Living in a remote area of the N.T. health care is very limited. We have private practitioners here who are good but very overworked. If you are not satisfied or want a second opinion, you have to fly to Darwin, at your own expense. Specialists visit here at an ad hoc [basis]. The doctors will refer you to a visiting specialist before referring you to Darwin.

I have recently had to resign from part time employment due to a back injury. My husband is on a Disability Support Allowance (since 1983) - old head injuries, we are very lucky that we have a supportive local GP. Sometimes, living in a remote area can be a drawback, eg. access to specialist services, however, if necessary I.P.A.T.S. covers visits to the city specialists - Otherwise we have to wait months for visits to the hospital for travelling specialists. I have to wait until mid-June for an orthopaedist, when I hurt my back mid-March. Luckily, intensive physio and pain killers are helping!

We are concerned about the level of other medical facilities in the country & the costs of air ambulances to be sent to Adelaide. This problem is going to affect us greatly if health services continue to move in the current direction ie few specialist services available locally & hence need to travel 380km & find & pay for accommodation in the city on top of stress!!

In addition to their greater demand for health services, middle-aged and older women who now find themselves living alone may be disadvantaged in a multiplicity of ways. Not only may they be experiencing stress and isolation following separation or the death of a partner, they may also find themselves members of 'the new poor'. For rural women, these disadvantages are magnified by the need to travel.

I find living in a rural area - that women have more problems because they don't have access to medical and health resources: the costs and the travelling are added burdens: Also there are the forgotten women - a whole section of women from the sixty's and seventies who were brought up to be house wives and carers who now find themselves in very stressful positions because of divorce or bereavement. With no job skills - not being able to find employment - not being eligible for a pension and trying to manage to live on unemployment which is \$159 per week: Because the ages of these women are from 45 - 65: employers overlook them because of the high wages involved. Job prospects for country women in this predicament are almost nil. This causes untold stress & financial hardship.

Small country hospitals are seen as particularly 'user friendly' for women, but there appears to be widespread unease about recent closures.

I suffered a very bad fall in the shower 6 months ago, resulting in a wedge fracture of a vertebrae. Could have been a lot worse and I am mending slowly. We have had 5 deaths of close family members in the last nine months, including my husband and several more close friends. Not exactly the best of years but I live in a close knit rural area and the support of family and friends (particularly church friends) has been absolutely wonderful! I have a very caring, wonderful doctor (country GP) who never seems to be in a hurry and a country hospital with a marvellous, caring staff. It would be an absolute disaster if it were ever to be closed as is happening to so many now.

May I say that smaller hospitals in the country do a great job too. It is a pity when they have to be closed they could be used as convalescent homes for old and infirm people, rather than closed. (We have lived in small towns and experienced treatment at Baradine, Manila and Kiama).

## ***Women as carers***

### ***Problems of access impinging on women's caring responsibilities***

Sick children have a great need for care and support, not least during hospitalisation, and the primary caring role is generally assumed by the mother. Women who have children in hospital are often torn between their responsibilities to the sick child and the rest of their family. This agonising dilemma is exacerbated by feelings of isolation when they need to travel to medical centres and are forced to spend extended periods away from home.

I have had a son with cancer for the last 3 years who went into remission last Christmas. Had to spend a lot of time in Adelaide with him as he could not get the care in the NT. I spent 3 months straight ... away from family and friends.

My husband has suffered three strokes and I am the carer. The apparent curtailment of health services ie. hospital, home care etc is very worrying. Distance is also a problem for country people when it comes to specialised care.

I am one of many such parents who have extreme stress by having a disabled daughter living permanently with us at home. In the past we had adequate respite to help us with this situation, but recently this has not been the case. In addition, we have my ageing parents living nearby who are now putting extra stress on the family with their medical conditions and reliance upon us to provide support with transport to specialists, etc., household maintenance, and general care. As you can appreciate, living in the country means travel to city for all of the medical problems associated with my daughter and also my parents.

When women seek health services for themselves, they often then have to make alternative arrangements for others currently in their care. Where they have children, they must organise childcare, for example. The further they need to travel, or the longer they are away, the more difficult this becomes and they may consequently limit the extent to which they seek help. There are implications here for their long term wellbeing.

My concern is deepening for the availability of relevant health services for women in small country communities like mine. Our poorer access to GPs and related services necessitates prolonged waits/delays, often causes excessive stress in even attending (time off work, eg. 1-2 days), difficulties with travel/child care arrangements associated with visits to specialists, health care centres, and has meant that I (and numbers of women in my district) have been very reluctant to seek help unless the need is urgent. In my recent experience, this has exacerbated health problems which may have been rectified/alleviated earlier.

### ***Service provision that 'works'***

Although many women were dissatisfied with health service provision in their area, there were others who wrote of services which had 'worked' for them. Women's Health Centres, mobile screening units, and nurses were found particularly useful.

My contacts with Women's Health Centres have been very positive - I have found them caring, professional, efficient. I have been especially impressed with follow-up service/care.

As I live in a rural area I would like to state my appreciation of some health services becoming more available in our region (ie mobile breast cancer van)

The mobile mammogram units are great and this service should be extended.

Question 12 asks have we consulted an allied health professional - but does not name "nurses". In the area that I live nurses underpin the health services. They are always available - they work as practitioners - and they are on call 24 hours a day. Although there are two doctors in this small community, they are not on direct call. All patients after hours access the nurses. The doctors are rarely disturbed. I am sure that there must be many areas in rural and remote Australia where nurses provide much of the primary and secondary health care which includes illness prevention, and health promotion.

One respondent outlined the way in which her community experienced healthcare services. She spoke positively, but nevertheless there are implicit questions here about quality, reliability and equity.

We are retired farmers living on the farm now owned by our son. We pay for electricity and phone but no rent. Our doctor is 80km away. We have a Community Health Centre in Moulamein with a nurse in attendance daily from 9 till 4 (except weekends) and a Women's Health Nurse attending regularly from Deniliquin. An ambulance manned by volunteers. A good service considering our geographical situation. A doctor visits one half day a week.

### ***Conclusion***

Women access health services as both patients and as carers, and experience more disadvantage than men because they are greater users of these services. Rural women are particularly disadvantaged in their restricted access. There is a lack of screening in some areas, and also a lack of medical specialists. The fact that rural women are more likely to have surgery is possibly a choice between a radical 'one-off' alternative compared to repeated and costly visits to a larger centre. Some concern was expressed about the closure of small country hospitals, which are perceived as more user friendly.

Women as carers, whether rural or urban, are often torn between their responsibilities, for example, between a sick child and the rest of the family, and this conflict can be exacerbated when women need to leave home for significant periods of time to travel or stay with a relative undertaking medical or hospital treatment.

Health services which were found useful included women's health centres, mobile screening units, and nurses.

### **(iii) Issues of healthcare costs relevant to women**

There are many ways in which women are disadvantaged financially in the health care system, both in middle-age and in their older years. Much of this disadvantage, however, is hidden. For example, there are a number of chronic diseases from which women disproportionately suffer and which often incur significant medication costs. As carers they also tend to have the responsibility for budgeting for healthcare and are likely to minimise their own needs. Furthermore, women make up the majority of those groups in our community, such as aged pensioners and single parents, who have the least access to financial resources and find themselves excluded from ancillary care.

The following discussion focuses on the costs associated with ancillary services and pharmaceuticals, and some issues around private insurance, which all impinge on women's health.

### *Ancillary services*

#### *Women as sole parents*

As women make up the majority of supporting parents, they often live in relative poverty - and some in absolute poverty. Irrespective of whether they receive the supporting parent's benefit or are employed, the cost of ancillary services for themselves and their children is often prohibitive.

There were no questions specific to be a sole parent which has unique problems. I have been in this situation twice where both husbands decided the grass was greener elsewhere and twice my life, lifestyle, finances, security, etc. was severely deprived. I chose to work throughout all these crises, but had no government assistance compared to those women who go on to the Family Support pension.

Also I would like to have greater access to dental and orthodontic services. As a sole parent I cannot afford these services. I have a 3-6 month wait for prescription reading glasses while looking for work. The hospital dentist would not fill one tooth claiming the job was "too difficult". My daughter has a major dental/orthodontic problem and I have been told only the "most urgent" problems will even be treated. I have worked and paid taxes for 28 years and now cannot obtain adequate medical treatment.

#### *Access and costs for rural women*

Problems of access for women outside urban areas, as discussed earlier in this report, present additional financial burdens which effectively bar them from ancillary services.

I wish dentists, podiatrists, opticians, chiropractors and naturopaths came under the health card system. I understand it is possible to attend the dental hospital in Perth to obtain free treatment but Perth is 350km away.

Going to a physiotherapist which is at the public hospital is impossible because of cost of taxis and availability of physiotherapist. There is no support in this area for people with disabilities in the workplace.

Periods of drought and resulting declines in family incomes have exacerbated the difficulties in rural communities.

Because of drought (exceptional circumstances) and hence reduced income. I've been unable to pursue problems with eyes (new glasses etc) because of cost involved purchasing such. Same applies to my husband. Dental visits are out for the same reason - visits to chiropractor reduced, all for the same reason. Thank goodness there have been no major medical problems over the past few years as I don't know how we would have coped financially.

### *Dental services*

As noted above, women who are sole parents are disadvantaged in their access to health services.

The only thing that I feel we perhaps lack is a readily available dental care. I, over the years of bringing up my son on my own and with working and looking after his health and dental foremost, never had the money to look after my own. Also, because I was a wage earner (and believe me it was the bare minimum paid to women) could not qualify for any help. This has over the years led to deterioration. As I am now unemployed (due to cutbacks at work, etc.) have had to seek health care help (I cracked my front tooth) - I am able to have emergency treatment (to the value of \$100), but further treatment will have to be put down on a waiting list. Although extremely grateful for this help, I wonder what the consequences will be when I do qualify.

However, a measure of the increasing inequality in Australia is the fact that not only are sole parents disadvantaged but that the single income family may also be unable to afford ancillary services.

(It is too expensive for us on one teacher's salary to afford any private health cover, or feel at ease when dental bills need paying ... It seems that the average person who tried to think correctly, eat well, exercise, etc. and has one normal wage per household, is disadvantaged compared to those who have health care cards, and are able to get free dental work done at hospitals (mouthguards for kids), free doctor and prescriptions, help at weight loss clinics, etc. and already receive in total as much finance per week one way and another as my family and I.

Similarly, dental care is often inaccessible for people on the aged pension, as well as for many self-funded retirees - and women comprise the majority of these older groups

The only matter I would like to solve is going to be able to afford the dentist for myself. (Husband a veteran so free for him). The Dental clinic is 25 miles away and waiting time to get in unless an urgent toothache is months long and waiting time in surgery is hours long. A local private dentist costs far too much.

The cost of dental services appeared to present widespread problems. It should also be remembered that the Commonwealth Dental Health program has been abolished since the survey was conducted.

I've had major dental work in the last 12 months. If anything has been physically or emotionally challenging it has been that. I've found dentists more arrogant and "do it to you" than doctors generally, ie. doctors of 10 years ago - their costs are outrageous and I don't believe they are always truthful about what needs to be done. Let's have a similar survey of "dental health"!

Several respondents claimed that dental care was important to them, as women, because bad teeth would affect their looks. While it is often argued that women should resist such manifestations of patriarchal oppression, nevertheless the competitive reality of the contemporary workplace means that their appearance is in fact important.

I have just finished a jobskill program and received 5 certificates in Admin office, I yet I have to wait for 1 and half years for dentures and have some bad teeth out. My appearance means a lot to receive work, that at the moment means a lot. Perhaps you could help me where to go.

Dental health: Very relevant especially in women. With lack of calcium and money its hard to keep on top of dental treatment. This affects one's health on a "slow drip" and also adds to depression about age and looks if teeth are bad. Dental problems don't seem to be taken into account when talking of health and I think dentists are so expensive women tend to put off much needed regular treatment.

## ***Pharmaceuticals***

### *Longterm medication for chronic disease*

As noted above, there are chronic conditions which are more prevalent in the female population and the costs associated with these conditions are often a burden.

I have had MS for 16 years. I am appalled at the lack of interest generally in MS given the percentage of male to female who suffer with this complaint. We now have our only EURE treatment (Betaferon) and the PBAC refuse to list it on the PBS. I am currently paying \$18,000 per year (\$1,500/month) or (\$375/week) - can you understand how frightened I am of going into a wheelchair? We are currently lobbying politicians to intervene and list this drug. This disease affects mostly females aged between 18 and 40. If we could all (there is a criteria) avail ourselves of "Betaferon" we could stay in the work force and not become pensioners. I am frightened, disgruntled and desperate. If I had AIDS OR "HEP C" I would receive FREE treatment [emphasis in original]

Migraine is more common amongst women than men, and is perceived as a long term disability by chronic sufferers who argue that the costs of pain relief are exorbitant..

I feel more help/assistance must be given to mild or severe migraine sufferers. \$80 injections and \$30 tablets are out of most people's reach. Monthly pain killing tablets at ... \$24 per month for min. ... is a huge cost added to this... Medication at affordable prices would also be wonderful. Migraines - diagnosed at 12 suffered from 7 to now 45. What a cost BUT ... (o)thers classify it as a mild illness. Live in My Head - eyes, ears, neck - almost for two-thirds of 38 years and see how "mild", as others describe it, is this - disability ILLNESS! [emphasis in original]

Special dietary products are expensive when they are needed for an ongoing condition.

I feel more public support should be given to people suffering problems such as coeliac condition eg provision of communal meeting venues at a health centre so that sufferers can engage in self help and receive periodic advice from health professionals. The necessary dietary items are not always available at food chains outside capital cities and all items come only at very high prices eg, 1 small load of breadmix bought or home made cost \$4 or more.

I had cervical cancer which was cured by 2 operations in 2 years (1994,1995) and 30 treatments of radiotherapy. However the radiotherapy severely damaged my small intestine so it can't digest food or pulsate and it also has 2 constrictions. Hence I can't eat food. I nearly died from malnutrition last year but external feeding has greatly improved my situation. My special nutritional liquid feed is very expensive - \$25.00 per day and the equipment costs about \$50.00 per week. Added to this, I often need antibiotics because my gut is unpredictable and I have 2 lots of vitamins plus juices and drinks. If I were in hospital or a nursing home the Gov't would pay for most of this but I

get NO SUPPORT while I am at home... The lifestyle of my family is affected by my health because of this. [emphasis in original]

While the aged pension provides some buffer against the cost of medication, even the minimal costs of pharmaceuticals are significant when held up against the real income provided by the pension.

I do have a problem with the cost of Dindevan. Last year's was \$544.92 ... so you see it is a lot coming out of my pension. Also I had to have my right eye frozen and the cost of theatre fees \$25. It adds up to a lot when you have not much money.

Both my husband and I are age pensioners, my husband being an invalid pensioner for 5 years before turning 65. We own our own home. This last 6 months money has become a little tight as we are both attending the Dr quite regularly and with the clinic we attend not bulk billing we are required to pay \$3.50 per visit. I need to attend the physiotherapist once a week cost \$7.00 at the local hospital and medication for both myself and husband costing from \$2.70 to \$4.50 a time the extra cost per week in the last 2 or 3 months has been approximately \$15-\$20 this sure makes a hole in the pension, the clinic also charges \$2.00 per repeat prescription my husband has a pacemaker and requires a lot of medication. Thanks for allowing me to have a gripe about something.

### *Private health insurance*

There is a perception amongst many women that private health insurance is 'not worth the effort'. They note, for instance, that there are no rebates for follow up of abnormal mammograms and pap tests.

I feel that, after urging by the AMA and media sources women are encouraged to have Pap tests, the least the Private Funds and the Government could do would be offer a rebate on the cost of the test. Being a member of a private health fund obviously makes one wonder why we waste our money by contributing - a case of being penalised by making the effort.

Another respondent argued that mammograms should at least be free when women were at risk.

... a free breast screening if abnormality found on a regular "ongoing" screening - under 50 years especially if in family history. Same with colonoscopies for those in "family" history category.

The quantitative data showed that approximately fifty per cent of women were privately insured for ancillary services, and that this dropped to approximately thirty per cent in the older cohort. The maintenance of private insurance is a particular burden for aged pensioners.

I find health insurance for ancillary services difficult to finance because of high premiums.

Trying to keep up Medicare cover imposes a strain on finances - I'm always trying to make ends meet. As my husband and I are on an aged pension - we would welcome a discount or rebate on hospital cover premiums which we pay quarterly.

I am very frustrated at this time because, to avoid the delay in the Public Health System and knowing I had surgery to consider I'd severe arthritis I joined a Private Health Fund and took out 100% hospital cover. After a Lumbar Fusion operation, I found I had to

pay \$1400 in medical bills to cover excessive over charging of specialists on the scheduled fee. On the surgeon alone, Medicare and my private cover paid \$910 and I had to pay \$908, is that expensive? I now need a knee replacement but how can I go ahead with that knowing I can't afford the specialists and physio fees on our pension as our sole income and with no savings, but who cares and who wants to know. In the meantime my name is on a 2 year waiting list for my knee. I'm still struggling to pay \$52 a month for my PHI [Private Health Insurance] because of possible heart surgery and pain will sometimes not wait 2 years. So that's my Catch 22. Best of luck in your research. NB The above \$1400 is being paid off at \$20 per fortnight.

Older women often experience a dramatic change in lifestyle when they are widowed, or an equally significant but delayed change after some years as the dependant of a self-funded retiree.

"Yes" I think my Medi Bank (Private) is getting too expensive, they do not allow for people who after being retired for many years do not have the same income. I have been annoyed at the number of people I know who have had to withdraw from Medi Bank Private as they say they cannot afford to belong to it any more. Women's Health may be able to look into this matter as there are a lot of ladies out there who certainly need help, most seem to be Widows living on the Pension.

When we (my husband or myself) visit a Dr we have to pay \$34 of which we receive \$20 back from Medicare. Needless to say we visit only when needed to. Bulk bill is only available to pensioner, as self funded retiree (we worked very hard) to enable us to do so.

Could the government allow self funded retirees a certain no. of medical services to be bulk billed as for pensioners? Once full MBF cover as we have (costing \$2,000 annually) was an insurance medically and made you feel secure. No longer, as it's only hospital cover. Could this not be allowed to cover the "gap". People would then be more interested in private cover.

My husband and I are self funded retirees. (my husband a fit 86 years, I 71). We have saved and forgone holidays over many years to avoid the need for a pension, and lower interest rates now affect our income. Many people in our situation avoid seeking medical attention even when it would be advisable, because of the big difference in the "excess of the prescribed fee" that the doctors charge - and this also for specialists, radiographers, etc. that may follow on. This means that free Medicare is a myth.

## ***Conclusion***

Much of the financial disadvantage which women experience as users of health services tends to be hidden. This masking occurs in several ways. For example, women suffer disproportionately from a number of chronic diseases which can involve significant pharmaceutical expenses. As carers they often bear costs incurred by the cared for or by the caring process. They make up the majority of sole parents, with the concomitant financial disadvantage of that positioning, including lack of access to ancillary health care and in particular to dental services. There are also issues of private health insurance which are particularly relevant to older women as widows or dependants of self-funded retirees.

#### **(iv) Health care services and the mental and emotional health of middle-aged women**

There were 866 comments coded under emotional and mental health for the middle-aged women. Because emotional health is an outcome of many different conditions, both physical and social, there are many themes which intersect with other areas of this report. Women who are concerned about being overweight report depression, women who are juggling time are stressed, women caring for disabled family members report poor mental health, women who are worried about work (both lack of and too much) are anxious and depressed, women who have experienced childhood sexual assault commonly report poor mental health. The following section is based on an analysis of a subgroup of 238 responses extracted using the key words ‘anxiety’ and ‘depression’, with an emphasis on the experiences with the health care sector reported by the women.

##### ***The place of emotional health in women’s lives***

The comments made here suggest that mental and emotional health are integral to women’s sense of their overall health and well being. Some women commented that mental health issues were not given enough of a profile in this study.

I think you didn't ask enough questions about mental health (mainly physical). I have suffered with anxiety, agoraphobia and panic attacks and depression for 28 years which has affected my quality of life greatly... I would love to see a proper study done in this area as I don't believe it is a chemical imbalance but an imbalance to chemicals that we eat or breathe..

This survey does not appear to address some issues I feel are important, eg Post Natal Depression and Mental Illness. I have personally suffered from both.

The only thing you missed in the area of Not ‘Outside’ stresses but ‘Inside’, eg gnawing feelings of insecurity or inadequacy which are hang-overs from the past...

You did not ask about drug dependence, suicide attempts, child abuse....

...I thought you would have included “Have you ever contemplated suicide?” and “Have you ever attempted suicide?” as this is very important information and statistics.

##### ***Causes of poor emotional health***

In their comments most women described the stresses they were under and the reasons for these. Naturally they were many and varied but the main reasons given were: family and relationships; ill health - both their own and family members; menopause; employment and financial issues; childhood traumas such as sexual assault.

##### ***Family burdens: hardly an ‘empty nest’ in sight***

The ‘plight’ of midlife women suffering from the empty nest syndrome is an enduring stereotype of middle-aged women. A few women did write about the loss they felt now that their children had grown up and left home.

Over the last 15 months I have been in the thick of the empty nest syndrome, so feel that my stress levels are higher than they have been for a long time.

However the most overwhelming comments were about the number of people in their family whom they spent time worrying about and caring for. The obvious group for whom these women felt responsible were ageing and ailing and dying parents.

My health since I gave up work has been a lot better, but now I am in a new stage of life. My mother needs a lot of attention as she lives alone and has had a heart attack and is very demanding, also I have my mother - in - law living with us. She is 87 and is very frail. So now I find myself wondering how can a person keep sane and healthy with every day problems.

However this concern extended beyond those described in the earlier section on caring in this report. It was not only the well recognised role of caring for ailing parents, disabled children and spouses but the emotional 'caring' which was still happening for those adult children who had left home, were unemployed, had drug and alcohol problems, separations and divorces, or perhaps just getting on with living their lives, which created psychological distress in these women.

Also, after your children leave the nest and live their own lives they create stress in Mum and Dad because their adult problems become your worry.

Everything that has happened in my life - I have just given up. I get depressed over my children a lot if their life isn't going right.

.....I'm like any normal mother - I worry about the children (adults) even tho' they are not living with us.....

The Women's Health Australia substudy, '*Experiences of women seeking help for psychological distress*', has investigated in more depth the reasons women gave for their psychological distress. Early results from this unpublished study show that family worries were the most often cited reason for a recent significant episode of distress.

#### *Physical ill health causing psychological difficulties*

Of the many women who wrote about the relationship between poor emotional health and physical ill health, most saw pain and disability causing depression.

I have an on going bowel problem which causes a lot of pain which lead to severe depression. 1995 June: Had second back op. after which had nervous breakdown. Still fighting to get over it. Have constant back pain, but can now walk and do housework and drive car. Take medication for breakdown.

While there was less emphasis on the role of emotional factors causing specific physical problems, it was often inherent in what they said. This woman, for example, detailed all of the events in the past 12-15 months - two significant bereavements, father's paranoia and dementia, son's divorce.

Why my health has declined in the past 12-15 months is that... I could not cope with all this pain and trauma and my body just went into shock.

#### *Menopause*

Almost 10% of women in this group referred to menopause as a concern..

Factors I assume are contributing to my poor health - menopause - aging parents - Distance = guilt (can't see them too often) - Dying parent (alcoholic /cancer)

The only thing I would like to say is 12 months ago I went through a terrible time. It could have been menopause or a mid life crisis and put myself and family through an unhappy time. But I think I can put my wellbeing now down to HRT even though I wish I did not have to take it because of the fear of cancer, but I feel so well now I am too scared to go off it!

..... because I feel you have skipped over menopause in this survey. In the past two years my life has changed dramatically. Since menopause I am no longer the happy, energetic, calm person I was. My physical and emotional wellbeing has been shattered.

I feel I am now coping with life OK but before I got hormone replacement therapy felt extremely desperate. I found an excellent lady doctor who got me back on track. The hardest part was having my husband (usually very understanding) turn against me and also my 4 grown up children.

Previous to the past 2 years or so since I developed clinical depression (which brought on panic attacks and severe agoraphobia) I hardly ever went to a doctor except for check-ups etc and to have the children. Over the past 2 years I have been to doctors, specialists, having counselling a lot. I feel it is due to hormonal imbalance due to being pre menopausal. Things are getting better SLOWLY.

Fears of menopause and associated mid life changes were also expressed.

.....I also am not really happy about the thought of menopause and what comes after.

Menopause is a personal concern - the unknown future!

I dread the thought of menopause. I think that I am going to shrivel up into an old woman.

### ***Treatment for psychological distress and mental ill health***

Many of the women made comments about the effectiveness of counselling they experienced and others about the inadequacy of mental health services. In the following discussion, women's comments about doctors, medications, counselling and access to services will be considered.

#### ***Doctors***

As would be expected there were positive and negative comments about the treatment given by doctors.

. ... All these things [bereavements, child abuse, poverty, divorce] and much more helped me on my way to nervous breakdown. Dr put me on HRT and Prozac, once weekly counselling and my life started to have meaning again.

Some women were not happy with being prescribed medication or the side effects from that medication.

I was quite happy with the treatment given for PND. I was VERY unhappy with the treatment for PTD [Post Traumatic Depression]. I believe that I was given excessive amounts - in combinations - of medication - which - in my opinion worsened the original problem. This has been confirmed by a Professor of Medicine in Qld - who

undertook - successfully - to de-toxicate me, although - that required a 3 week hospital stay as an in-patient, followed by several weeks of "self" reduction of medication until all such drugs were ceased.

It took a year of constant visits to GPs before I was finally referred to a psycho for depression following 3 major ops within 12 months. My health then gradually returned to some normality. I don't visit Drs now if I can possibly avoid it.

During my most desperate moments I must admit I got more satisfaction and understanding of what was happening to me through books at the local library, eg. stress, depression, menopause, than I did from any doctor.

### *Medications*

In relation to psychotropic medications, women seemed very matter of fact, even resigned, '*I had to go on antidepressants*'. The prevalence of women's use of prescription medications for mental health problems cannot be estimated from the WHA data, but 6.5% of women reported taking a tablet 'for nerves' in the past 4 weeks.

Have a history of depression which has had a major influence on the course of my life, but in recent years the use of anti-depressant drugs has vastly improved the quality of life and self esteem.

However the voice of acceptance was not the only one. There were also women wanting to cope without recourse to 'unnatural' medications - whether antidepressants or hormone replacement therapy.

In the last six months I have had an antidepressant prescribed which has made me feel like my old self (ie what I was about 3 or 4 years ago). This has been a salutary experience as I have always thought I was a good 'coper'. I would very much like NOT to be taking any medication but my normal resolve to stay natural is outweighed by the effects of hormonal change.

I have suffered form agoraphobia for the past 6 years and, because of the nature of the complaint, there doesn't seem to be adequate help anywhere. My GP was sympathetic and the psychiatrist he sent me to was sympathetic, but because I didn't want to take any drug, it seems to go into the "too hard basket". I have been fighting it myself, with some success, but it makes you very exhausted an you wish there was someone or place with expertise to help you along.

Psychiatrists, of whom I've seen 3, seem to think problems [agoraphobic suffering panic syndrome, anxiety and depression] will be solved with anti-depressants. These drugs, including the much touted Aurorix either increase my problems or at best, do nothing for my symptoms.

It is hard to find help that you don't have to use drugs. I had to wait on a list before I could see a counsellor.

The following quote illustrates an attitude demonstrated by a number of women. They saw mental health difficulties as being in the province of medicine; they consulted medical practitioners for help but did not see drug therapy as being appropriate treatment for them. This woman describes a form of treatment which she experienced as helpful and positive.

I suffered a fairly bad bout of depression for about 9 months of last year, mainly due to changes - finishing thesis, child starting school, end of long term job leading to questions about whether to change career - "mid life crisis". There may also have been some hormonal aspect. In deciding to check the latter out, I opted to change to a woman doctor, as I knew my (male) doctor is very gung-ho with medication and would immediately put me on HRT, assuming a woman of my age would need it. The woman doctor helped a lot - lent me videos on menopause and depression, let me talk a lot, discussed drug options (ie anti-depressants) - what helped most was she really accepted what I said and seemed to grasp the whole confused mess - affirmed my strengths but also let me know she was there to offer support/help if I needed it - AND did not push the drugs.

### *Positive effects of counselling and 'therapy' by mental health professionals*

For some women counselling had been a great success. After severe and long term emotional problems, relief and a chance for a better life was in sight for some.

Apart from allergies, migraine and past obstetric problems my health problems are due to anxiety due to disordered childhood & past partner relationships. These I am dealing with a psychologist. As a consequence my health in the past four weeks (literally) has been excellent; for the previous 1 1/2 years it was diabolical; and for the previous 25 years, poor due to chronic anxiety, depression, allergies & obstetric/gynaecological problems. Psychology should be provided on Medicare.

In the last three months difficulties with our teenage daughter have greatly contributed to our stress levels and impacted on other aspects of our lives - and there seems to be no readily available support for most parents in this situation. We know it is a common problem. (Luckily we have had good support from family and friends and access to personal counselling through an Employee Assistance Program).

I am currently in therapy with a psychotherapist. This started when I had severe depression and pre menstrual tension. I think this was a hangover from post partum depression that never entirely went away. ( It was untreated at the time - didn't think there was anything that could be done). My quality of life has improved out of sight since having the therapy. I no longer have depression or PMT but it is like a "support" in my life - something that keeps improving my life week by week. I find it invaluable.

Prior to '94 I had bulimia and went to counselling for repressed anger towards my husband They helped me tremendously to stop focussing my life around my husband. Since counselling I have spent a lot more time on myself and stopped worrying about my weight....I have learned to like myself again....

In mid 1993 I had major depression and tried to take my own life. I was under the care of a psychiatrist for 18 months and have made a pretty good recovery since.

Although bereavement was one of the most often mentioned sources of distress, very few respondents mentioned receiving counselling services for this. This rural woman's 19 year old son had been killed in a road accident 20 months previously.

These problems are worse now than 12 months ago, although I voluntarily sought recent grief counselling which helps a bit.

### *Dissatisfaction with mental health services*

The main comments here revolved around the cost of counselling and the lack of appropriate mental health services; there were very few comments about poor services.

History of chronic depressive illness during last 20 years. Hospitalised few times, last 12 months have noticed significant improvement. (Mental health department and availability of understanding professionals non-existent).

I would like to have more help with my constant depression, there seems to be little help available for mental health.

A lot of questions concern the last 12 months. It is not a good time for me. I have become separated from my husband and had to declare bankruptcy due to my husband's failed business. So a lot of stress due to this. This is not my normal state of health. I feel I need counselling but can not afford the cost. My 12 year old daughter would probably benefit from some form of counselling but I am not aware of any available at no or low cost.

Suggestions by respondents for improved services come under the broad headings of lowering costs and increasing the availability of counselling services. It is possible that women would be more likely to consult a private counsellor than a GP or specialist psychiatrist if counselling services by psychologists and other counsellors were not so expensive. One respondent suggested that '*Psychology should be provided on Medicare*', and this was echoed in the comments of others.

I suffer from severe depression and I am taking Prozac as medication (prescribed by specialist) As my specialist has passed away I am being supervised by my GP, as it is very difficult to see another specialist. I feel that psychologists should be covered by Medicare for not so urgent cases as myself. Psychologist[s] should work in conjunction with my psychiatrist for supervising medication.

I feel partners, spouses, and children of alcohol and substance abusers need counselling, understanding, and care, eg. by psychologists, and therapists, etc, to be free of charge. Some of these services are very expensive and therefore traumatised persons forfeit getting any emotional help or support, because of lack of money, therefore suffer alone.

In dealing with life after a divorce the main problems are finance, support for self and caring for children, securing for the future which leaves a big black hole. It is a time when women need so much help. Counselling is very expensive and not readily available to help with depression and advice in caring for children who also need special care. I believe councils should look at providing home help, maintenance men - having to maintain a house without carpentry/plumbing knowledge and no finance to pay is frightening. You feel very helpless.

There were comments about the stressful nature of living in remote areas and small towns but the comment from this farming woman whose husband had died after a terminal illness gives special insight.

There was support available in the city - but that's not where I was! My suggestion - some specialist counsellors in a service which allows them to assist people in other communities than their own; the people who need help being those who can't find it for "socially, isolating" reasons - eg. if you are playing a role in a community which makes it difficult to seek help for yourself within the normal service alternatives available to that community.

## ***Conclusion***

With the exception of menopause, and as a direct result of illness, the factors women wrote about as causing their mental health problems were overwhelmingly social and economic in origin.

....I also have clinical depression, due partly to being a sole parent, full time worker, and completing my PhD...

My major health problems stem from emotional problems which stem from childhood neglect and abuse which stemmed from poverty, lack of education , lack of social support and cultural socialisation.

It would seem that women consult their general practitioners for help for psychological distress while being very aware that the feelings they are experiencing are the result of the many burdens they carry, either as a result of childhood traumas or of more recent family troubles, or illness (or sometimes all of these) which they and others see as part of their 'womanly' roles. That the help offered is often of the pharmaceutical kind is accepted by some women and found wanting by others. The benefits of counselling reported by some women suggested life changing directions. Suggestions for improvement centred around increasing the availability of counselling and reducing the costs. Specific suggestions about being able to claim for counselling on Medicare were made.

The following comment puts the view of those women who are asking for an alternative to medications for their socially caused depressions.

Recently I experienced deep loneliness and sadness (not depression) and my GP suggested an anti-depressant. I refused to try out the drug as my feelings are important and an indicator as to my mental health. As distressing as it may seem to others, people's feelings must not be treated with chemicals. Women, wives and mothers often 'carry' the unexpressed feelings of the whole family unit.

Not only do women carry the unexpressed feelings of the family but also the expressed physical and emotional caring for their extended families.

### **2.3.6 CONCLUSIONS**

The qualitative data show that women in Australia experience fundamental conflicts of interests and concerns which impinge on their health. The interrelationship of these conflicts and concerns mediates against the isolation of discrete issues in women's health. It is well established, for example, that women do a disproportionate amount of family work. They are therefore likely to become time stressed if, as is increasingly occurring, they undertake paid work. However, a new element of anxiety is the uncertainty about unemployment in the contemporary economic climate and this has further particular implications for women, who are over-represented in the numbers of sole parents. Furthermore, women who have left a violent relationship are subject to multiple layers of tension and anxiety.

In their role as carers, women experience tension over financial interests, the distribution of time, of lost opportunities, of the inability of the carer 'to adequately meet the needs of the cared for'. Such tensions add to the problems of access and costs for women in health service provision. Particular health issues of weight and exercise also intersect with issues of time use and caring. Carers and working women are both constrained in their ability to undertake exercise, and while there is an understanding about the health consequences of remaining overweight, the connections between lack of exercise and the 'tiredness' about which many women complain are less well understood by the wider community.

Within health service provision, women have some significant concerns. One of these is the scarcity of women doctors, particularly female general practitioners, who demonstrate a particular approach to medical practice which is sought by many women. This scarcity encapsulates the conflicts and constraints experienced by many women in that it is aspects of the gendered nature of the labour market which is implicated in the lack of female GPs.

In their access to health services, women are more disadvantaged than men because they are greater users of these services, both as patients and as carers. As the qualitative data show, rural women are particularly disadvantaged and this is borne out, for example, by higher rates of hysterectomy in rural areas. It is likely that women choose surgery as their preferred option, rather than undertaking repeated and costly journeys to consult specialists in urban centres. Women are also susceptible to financial pressure from health care costs, but much of this pressure is hidden.

The factors women wrote about as causing their mental health problems were predominantly social and economic in origin. Similarly, older women who have been widowed have needs which encompass health, social and financial aspects and not just emotional distress.

While this present report has necessarily dealt briefly with some of these issues, the qualitative data will be explored in further substudies, including matters such as eating disorders, caring and health, social support for older women, and midlife weight gain, to illuminate the complexity of the social and economic backdrop to the quantitative findings of this project.

### **3. MEDICARE CONSENT**

### **3.1 INITIAL REQUEST FOR CONSENT TO ACCESS HIC/MEDICARE DATA**

In March this year all women who completed the baseline survey and consented to participate in the longitudinal study were sent a letter requesting their consent for the researchers to access HIC/Medicare data. A copy of the letter and consent form are shown in Appendix 3. A summary of responses to this first request is shown in Table 3.1

**Table 3.1 Response to initial request for consent to access HIC/Medicare data in the three cohorts**

	<b>Young</b>	<b>Middle</b>	<b>Older</b>
Requests sent	14,192	13,712	12,042
Number (%) returned in one month	4578 (32%)	7115 (53%)	5839 (48%)

### **3.2 TELEPHONE REMINDER**

One month after the initial mail-out, randomly selected young and middle-aged women living in NSW, who had not responded, were telephoned to ask whether they had received the request, and whether they intended to respond.

Of the women contacted, 19% said they had not received the first letter. The majority of these women had changed their address since the baseline survey. A further 13% had lost the letter, and the rest had either already returned the consent form, or were intending to do so. A minority (6%) had decided not to consent. Table 3.2 summarises the outcome of this reminder strategy, four weeks after the telephone calls were made.

### **3.3 MAIL REMINDER**

Five weeks after the initial mail-out, the remainder of non-responding NSW women in the middle and older cohorts, and randomly selected non-responding young, middle and older women throughout Australia were sent a reminder letter by mail. The response to this mail reminder strategy is shown in Table 3.3.

**Table 3.2 Response to telephone reminder - selected women from the young and middle cohorts living in NSW**

	<b>Young</b>	<b>Middle</b>
Number of women telephoned	375	272
Number uncontactable (moved or not available)	178	81
Number of women contacted	197	191
Number returned with consent (% of those contacted)	65 (33%)	78 (41%)
Number not consenting (% of those contacted)	33 (17%)	23 (12%)
Number - no response (% of those contacted)	99 (50%)	90 (47%)

**Table 3.3 Response to mailed reminder - selected women in the three cohorts**

	<b>Young</b>	<b>Middle</b>	<b>Older</b>
Reminder sent	906	2,422	2,582
% returned - consent	9%	20%	20%
% returned - non consent	4%	2%	2%
% not responding	87%	78%	78%

### **3.4 FINAL RESPONSE TO REQUEST FOR CONSENT TO ACCESS MEDICARE RECORDS**

To date, 18,769 participants have given consent for the researchers to access their HIC/Medicare data (see Table 3.4). This represents overall response rates of 33%, 56% and 53% for the young, middle and older cohorts respectively. The additional reminder strategies used in NSW increased response rates in that State by 9% in the middle cohort and 6% in the older cohort. The telephone reminder, although more expensive, resulted in a greater response rate, and had the advantage of assisting to locate women who had changed address since the baseline survey last year (see Table 3.4). The NSW participants in the middle and older cohorts will be the participants in the sub-study to evaluate data linkage methods (see Section 4.1).

**Table 3.4 Summary of responses for request to access Medicare/HIC data in the three cohorts (NSW participants shown separately)**

	<b>Young</b>	<b>Middle</b>	<b>Older</b>
Total number of requests sent	14,192	13,712	12,042
Number returned to sender	568	192	79
– new address found & re-sent	383	88	36
– location currently unknown	203	104	43
–			
Number of participants NSW	4116	3820	4094
Number consenting NSW	1,355	2,477	2,390
Response Rate NSW	32.9	65.0	58.4
Number of participants -Other States	10076	9898	7948
Number consenting Other States	3,366	5,211	3970
Response Rate Other States	33.4	52.6	50.0
<b>OVERALL</b>			
% indicating non-consent	3.2	3.0	1.2
% from whom no response received	63.5	41.0	46.1
Final response rate (26 May 1997)	33.3	56.0	52.8

## **4. REPORTS ON SUB-STUDIES**

### **4.1 HEALTH SERVICES UTILISATION**

*PhD candidate:* Anne Young

*Supervisors:* Professor Annette Dobson, Dr Julie Byles

#### **INTRODUCTION**

The purpose of this study is to identify factors which are important in explaining the use of health services by Australian women. By using a variety of multivariate statistical analyses, this research will enable us to identify those factors most important in explaining and predicting the use of health services. The findings are intended to be useful to those planning and developing services and health policies relating to Australian women.

Research on the health care system has identified a number of factors related to the use of health services. Andersen and Newman have formulated a model that incorporates many of these factors. This model has been chosen as the theoretical framework for the present research project and statistical methods to implement the framework will be investigated. The explanatory components of the model are labelled predisposing (the predisposition of the individual to use services), enabling (the ability to secure services), and need (the need for services). A diagram of a recent version of the model is shown in Figure 4.1 below. It includes health status outcomes and portrays the multiple influences on health service utilisation and health status. Feedback loops show that outcome, in turn, affects subsequent predisposing factors and perceived need for services as well as health behaviour. A central question in health services research is whether the services are used according to need or not and if not, which factors can be modified to increase equity in the use of services.

The design of this research project follows recommendations given in previous studies on the use of this model, which include incorporating the context in which utilisation occurs, examining different age groups, examining disease-specific utilisation, modelling high levels of utilisation separately and using innovative types of statistical analyses.

#### **AIMS**

*Aim 1:* To use record linkage of self reported survey data and Health Insurance Commission (Medicare) records to provide a measure of general practitioner and specialist utilisation patterns.

*Aim 2:* To assess the relative explanatory power of three sets of factors (predisposing, enabling and medical need) relating to health service use, by estimating additive and interactive linear regression models, structural equation models and multilevel linear models, for women in each age cohort separately.

*Aim 3:* To assess the adequacy of these models for predicting health service use in subgroups of women, including frequent users of physician services, non-users and

women reporting similar levels of medical need, such as those with diabetes and severe menstrual symptoms.

## **DESIGN**

### **Data sources**

Using baseline data from women enrolled in the Australian Longitudinal Study on Women's Health, this project will estimate cross-sectionally, the relationships hypothesised in the model of health services utilisation. Data on predisposing, enabling and need variables were collected in the questionnaire completed by the three cohorts of women during April to September 1996. The variables of interest include age, education, marital status, satisfaction with medical care, use of preventive services (predisposing characteristics), occupation, insurance, geographic location (enabling characteristics), the SF-36 dimensions of physical and mental health-related quality of life and the number of physical conditions and symptoms (measures of need).

Data on utilisation of health services, in particular general practitioner and specialist medical services, will be obtained from the Health Insurance Commission (Medicare). For those women who provide written consent for Medicare to release their individual information, the research team will obtain unit record data for every claim for medical services for the last two years. The records include details of the item number of the service, the age group, postcode and speciality (if any) of the service provider and a scrambled provider number. Information on the cost and date of the service will also be included. For women who do not consent, aggregated data will be obtained.

### **Record Linkage**

The information from Medicare will be linked to each woman's survey record to provide a range of demographic, social and health service utilisation variables. This provides an excellent opportunity to investigate the predictors of health service utilisation. In general, national data sets lack individual information such as health insurance coverage, social supports, health beliefs and levels of physical and mental health status and functioning. No other national data source has such a full and detailed assortment of multiple indicators of the predisposing, enabling, need and health service utilisation characteristics of a random sample of the population.

### **Additional questionnaire**

Length and time limitations on the baseline questionnaire did not permit collection of data on all variables specified by the model. Hence, a further questionnaire will be sent to women in the middle and older age groups living in New South Wales to provide more detailed information on predisposing, enabling and need variables in this subset of women. It is anticipated that the consent rate to access Medicare information, the use of services and the prevalence of symptoms, will be higher for these women than for the younger women. The model will be tested in New South Wales in the first instance as this will facilitate obtaining information on population variables. As well, all women across Australia in the middle and older age groups who answered that they had ever had diabetes will be included in the additional survey.

### **Statistical Analyses**

The analyses will include a range of statistical techniques to examine the complex relationships among the variables. The traditional method of linear regression will be extended to incorporate multilevel modelling to ascertain the effect of area of residence on health service utilisation. By working at more than one level, the context in which individual utilisation occurs can be modelled. This will help to answer the question of whether differences between areas in health service utilisation are solely attributable to characteristics of people living in them or whether there are area effects. If there are area effects, the analyses will estimate to what extent they are explained by area level variables, such as a measure of remoteness or supply of medical services and personnel.

## **PROGRESS**

### **Literature review**

A review of the literature was undertaken in the following areas: record linkage, privacy, confidentiality, health services utilisation, patient satisfaction, the Andersen-Newman model, the health belief model, access to health services and equity of use of services, multilevel (hierarchical) modelling, structural equation modelling and path analyses. This review has informed the development of the request for access to Medicare records, the content of the additional questionnaire and the plan for data analyses.

### **Consent to access Medicare records**

Focus groups of women in each age group were conducted to determine their level of knowledge about the Medicare database and their concerns about a research team having access to Medicare records. Following these focus groups, a consent form and an information pamphlet addressing the main issues of concern were drafted and pilot tested. Minor modifications were made to these forms, which were then approved by the University of Newcastle Human Research Ethics Committee, the Department of Veterans' Affairs Ethics Committee and the Health Insurance Commission.

A request to obtain consent from women in the main study was sent during March and April 1997 and yielded a consent rate of 50% in the middle aged and older aged women and 25% in the younger women. A reminder letter and a replacement consent form and pamphlet were posted to mid and older aged women in New South Wales and women with diabetes in the rest of Australia. It is hoped that this reminder will increase consent rates to 70% for these women.

### **Liaison with the Health Insurance Commission (HIC)**

Medicare consent forms for women from Pilot 1 were sent to the HIC in January 1996. A file containing details of the Medicare services rendered during the 1994 and 1995 calendar years for those women was received in March and updated in October 1996. Around 15,000 services were rendered by the 578 women for the two year period and data analyses programmes have been tested on this dataset.

Negotiations are underway to finalise the protocol for sending consent forms for women in the main study to the HIC and receiving the Medicare and Department of Veterans' Affairs (DVA) histories for the consenting women. The HIC is able to identify women who receive benefits for medical services from DVA as the HIC also processes those claims. Approval to obtain this information has been given by the DVA Ethics Committee.

### **Women's satisfaction with general practice consultations**

A paper has been submitted to the Medical Journal of Australia describing the levels of satisfaction with general practice services among the women in the study. The abstract from this paper appears in this report. Consumer satisfaction is one of the outcomes in the Andersen-Newman model and is thought to be associated with environmental and population characteristics. Levels of satisfaction with most aspects of the last visit to a general practitioner were very high, with increasing levels of satisfaction with increasing age. The visit overall was rated as good, very good or excellent by more than 80% of women.

### **Design and implementation of the additional questionnaire**

The additional questionnaire is currently in draft stage and will be submitted to the University of Newcastle Human Research Ethics Committee for approval, prior to pilot testing. It is planned that the questionnaire will be sent to 8,000 mid and older age women in New South Wales around August, 1997.

## **4.2 IRON DEFICIENCY IN WOMEN OF CHILDBEARING AGE**

*PhD candidate:* Amanda Patterson

*Supervisors:* Dr Wendy Brown (principal supervisor), Professor David Roberts (associate supervisor)

### **INTRODUCTION**

Iron deficiency is the most common nutrient deficiency in the world, and it is particularly prevalent in women of childbearing age. Despite the fact that one in twelve Australian women is affected, little is known about the health effects for these women. Similarly, little information is available about the development and treatment of iron deficiency for Australian women. This research includes three studies which encompass the development, affect and treatment of iron deficiency for Australian women.

#### ***4.2.1. Analysis of Women's Health Australia Baseline Data***

*Rationale:* The development of iron deficiency in women of childbearing age is thought to be associated with heavy menstruation and number of children. Certain lifestyle factors such as exercise, dieting, contraceptive choice and alcohol intake are also postulated to play a role. However, this has not been confirmed, and little data exists for Australian women.

Iron deficiency has been shown to be detrimental to work performance, behaviour, immunity and thermoregulation. The relevance of these effects to typical Australian women is unknown. It is a widely held belief that iron deficiency is associated with fatigue, but there are no data to support or refute this. It may be that the individual effects of iron deficiency combine to produce a significant reduction in general well-being for Australian women, or iron deficiency may be inconsequential.

*Aims:*

1. To investigate associations between a history of low iron and factors thought to influence its development.
2. To examine possible effects of iron deficiency on general health and well-being for Australian women.

*Design:* Baseline data (mid-cohort) from the Australian Longitudinal Study on Women's Health (ALSWH) has been examined for associations between a history of low iron and parity; heavy menstruation; alcohol intake; exercise; body mass index; dieting history; oral contraceptive use and constant tiredness. Mean SF-36 scores have been compared for those with and without a history of low iron.

*Progress:* Analysis of data has been completed and a paper has been submitted to the First National Women's Health Promotion Conference (see abstract for results).

#### **4.2.2. General Practitioner Survey**

*Rationale:* Diagnosis and treatment of iron deficiency is a role of General Practitioners. It can be postulated that most iron deficiency in Australia is treated with iron supplements, but no data regarding treatment practices is available. Nor do we know GP's attitudes regarding the relevance of this issue for women of childbearing age.

*Aim:* To determine knowledge, attitudes and behaviours of General Practitioners with regard to diagnosis and treatment of iron deficiency in Australian women.

*Design:* Anonymous self-report questionnaires mailed to all GP's in the Hunter Valley. Surveys returned in reply-paid envelopes.

*Progress:* The questionnaire has been designed in co-operation with the Hunter Urban and Rural Divisions of General Practice. Ethics approval has been obtained. The surveys are scheduled to be sent in July, and data analysis will follow.

#### **4.2.3. Intervention Study**

*Rationale:* Studies suggest that iron status is not determined by total iron intake, but is more dependent on haem iron intake. Absorption of iron is enhanced by muscle protein, vitamin C and alcohol and inhibited by tannins, phytates and calcium. Thus there is abundant information on the individual effects of these compounds but little on their role in determining actual iron status.

It appears that most guidelines regarding the treatment of iron deficiency refer only to the prescription of supplemental iron. Compliance with iron supplements has been shown to be poor for many reasons, including gastrointestinal side effects. Dietary assessment and advice should be an integral component of treatment, especially if poor diet is a causative factor, and has long-term advantages for the maintenance of iron status.

Cross-sectional data from the ALSWH baseline survey suggests that general well-being may be decreased and fatigue increased with iron deficiency. This needs to be investigated using a stronger methodological design.

Cognitive functioning and mental performance have been shown to be impaired in iron deficient infants and children. Few studies have been done in adults, but there appears to be a similar decrease in mental performance. There are obvious major implications for decreased performance in all areas of life for Australian women if this is indeed the case.

*Aims:*

1. To determine which dietary and lifestyle factors influence the relationship between iron intake and iron status in Australian women of childbearing age.
2. To determine whether iron status in iron deficient women can be effectively restored and maintained with dietary intervention alone.
3. To determine whether general well-being is impaired in iron deficiency and whether it can be improved with the restoration of iron status.
4. To determine whether fatigue scores are increased in iron deficiency and whether they can be improved with the restoration of iron status.
5. To determine whether cognitive functioning is impaired in Australian women of childbearing age in iron deficiency, and whether it can be improved with the restoration of iron status.

## **DESIGN**

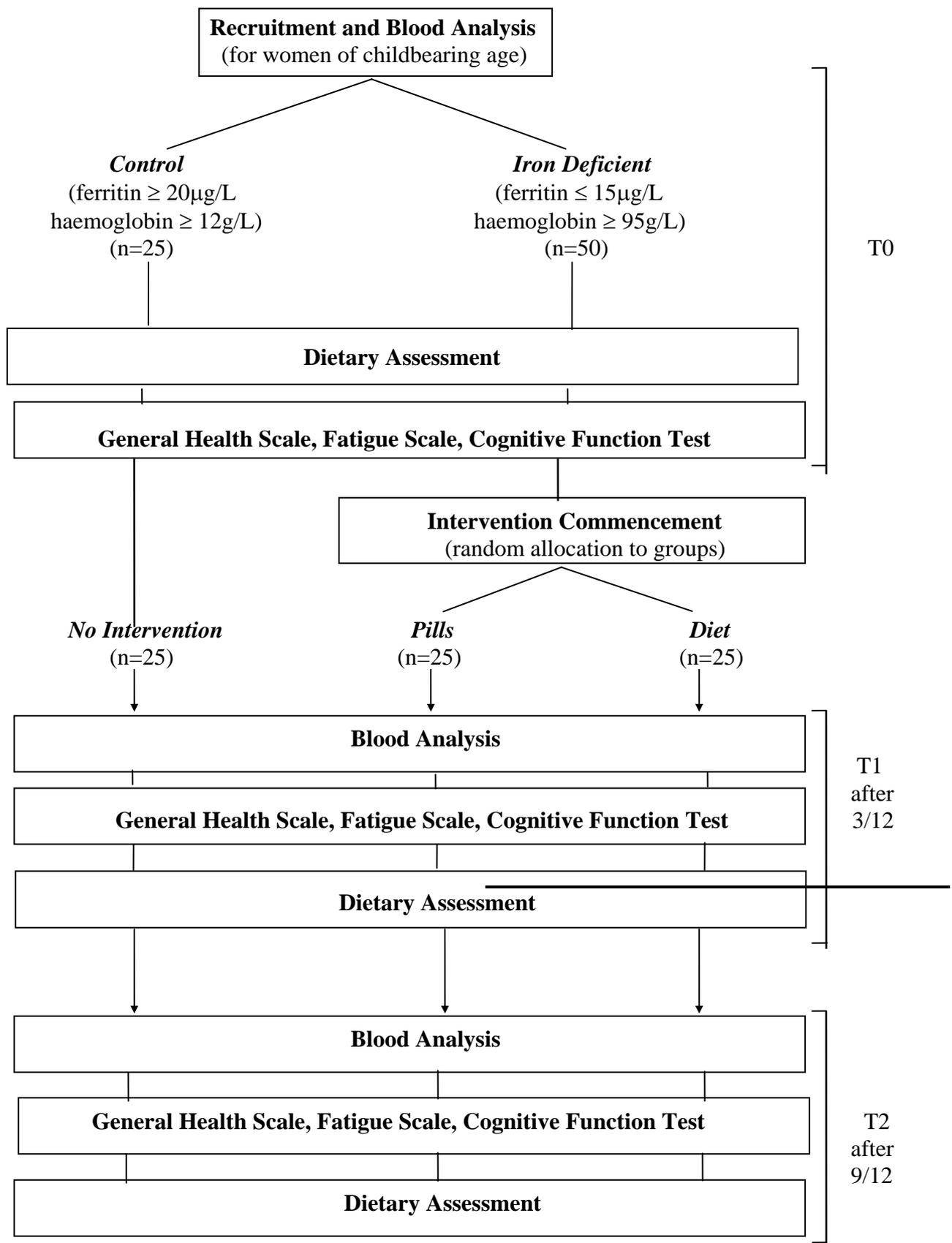
A flow diagram of the research protocol is shown in Figure 4.2.

**Recruitment:** Iron deficient women are being identified by local pathology laboratories, who have agreed to attach a letter for general practitioners to all results showing low iron levels. At the GP's discretion, iron deficient women will be informed of the study and invited to telephone the researchers. Entry criteria include: women must be premenopausal, non-pregnant and have no major organic cause for their iron deficiency.

**Assessment:** Dietary intake is being assessed using Seven Day Weighed Records of all food and drink. Dietary data is entered into the 'Diet 1' nutrient analysis program (version 4), and exported into Microsoft Excel to allow more sophisticated analysis.

Each woman in the study is also requested complete the SF-36 General Health Questionnaire, and the Piper Fatigue Scale. Attention and concentration are assessed by a psychologist using four subscales of the Wechsler Adult Intelligence Scale (Digit Span, Digit Symbol, Block Design, Arithmetic). Information about demographics; parity; oral contraceptive and IUD use; HRT; smoking and alcohol; exercise; weight and dieting; blood donation; supplement use and menstruation is also being collected.

**Figure 4.2** Flow diagram of proposed research protocol



**Interventions:**

1. Iron Supplements - Ferrogradumet, a commonly prescribed iron supplement, has been supplied by Abbott Australasia. Women in the supplement group are requested to take one tablet per day as per the directions of the manufacturer for the three month intervention period.
2. Diet - Women in the dietary intervention group are asked to adhere to the following daily dietary guidelines for 12 weeks:
  - 1 serve of high iron food - approximately 120g cooked lean red meat (supplied by the Australian Meat and Livestock Corporation)
  - 1 serve of medium iron food - approximately 60g of white meat or 1 cup of pasta or 1/3 cup of legumes
  - 5 serves of low iron foods - breads and cereals, eggs, green vegetables etc.
  - Absorption enhancers at each meal (eg vitamin C rich foods or meat)
  - Avoidance of tea, coffee and milk as the beverages at mealtimes
  - (Combinations of the above foods to provide equivalent iron have been calculated for those who do not wish to include red meat every day).

**Follow-up:** All tests are repeated at the end of the 12 week intervention period. There is no intervention during the following 6 months, after which blood iron levels are re-assessed to evaluate the longer-term effects of the two interventions.

## **PROGRESS**

Twenty three women are currently enrolled in the study (14/5/97) and have completed the first phase (T0). Recruiting through pathology labs and GP's has not provided adequate numbers of participants so ethics approval has been sought to advertise for volunteers.

Diet 1 provides only total iron intake, so the program has been altered to allow the assessment of both haem and non-haem iron intakes. A Microsoft Excel program is being written to calculate the bioavailable iron content of the diets. This is the first time this has been done using actual haem and non-haem iron contents. In the past, an estimation of 40% for haem iron contents of meat, fish and poultry has been used, while in reality, the contents vary from 17-70%. The results of this work will be submitted for publication later this year.

### **Additional information**

A literature review has been completed and a modified version has been submitted to "Nutrition Research" for publication. Data from a local pathology company have been analysed to investigate the relationship between clinical reports of fatigue and iron deficiency. The results suggest that one in three iron tests done on the basis of tiredness alone is positive for iron deficiency. There are also some interesting age and gender differences. If the pathology company consent, we will publish these data later this year.

## **4.3 DISORDERED EATING, PSYCHOLOGICAL STRESS AND COPING IN YOUNG WOMEN**

*PhD candidate:* Kylie Ball

*Supervisors:* Dr Christina Lee (Interim supervisor: Dr Wendy Brown)

## **BACKGROUND AND AIMS**

Disordered eating, particularly among young women, has in recent years become the focus of increased research, clinical and public interest. Etiological research into eating pathology has identified a number of factors which may be precursors to disordered eating, including psychological factors such as poor body image, low self-esteem and depression. One factor which has recently received increasing research attention as a possible precursor to disordered eating is psychological stress, with numerous studies reporting an association between psychological stress and disordered eating. However, a number of problems with the current state of this research remain to be addressed. For example, why does psychological stress appear to be associated with disordered eating in some women and not others? Is the role of coping skills significant in mediating different types of stress among women with eating disorders? Do other factors (e.g., body weight/shape dissatisfaction, depression) mediate this relationship? In addition, prior studies have employed a multitude of different assessment instruments, with inadequate regard for precision or consistency in the assessment and quantification of stress or disordered eating. An additional problem is that the majority of studies which have suggested an association between psychological stress and eating disorders are correlational in nature, and many utilise retrospective, self-report methodologies. This makes it difficult to determine the importance of the role of stress processes in the onset and/or progression of disordered eating, and to establish conclusively the direction of causality of this effect.

The proposed study aims to address these issues and to investigate the relationship between psychological stress and disordered eating, in a cohort of young women (aged 18-22 years). The utilisation of a longitudinal study design will enable an examination of the temporal order of occurrence of these factors, which should enable conclusions as to the role of stress in the onset or worsening of disordered eating to be established.

## **DESIGN AND PRELIMINARY RESULTS**

The study will comprise several smaller sub-studies, including:

### **1. An analysis of existing WHA pilot data**

**Design:** This was a preliminary, exploratory sub-study examining data collected in the WHA pilot 1 study. The main aim of the study was to investigate the relationships between psychological stress and disordered eating patterns in this small group of young Australian women. The subject group comprised the young cohort, 212 women aged 18-22 years who completed and returned the Pilot 1 questionnaires.

The questions/variables used in this substudy were:

- Life Events: Scales modified from Norbeck (1984)
- A single question assessing perceived stress levels: “How often do you feel under stress?”

- The GHQ-12 (General Health Questionnaire) to screen for general psychological distress
- Questions on disordered eating behaviours (presence and frequency of episodes of binge eating, vomiting, laxative and diuretic use), attitudes (thoughts of food interfering with life; feelings of guilt over eating), and discrepancy between actual and ideal BMI.

Correlational analyses were conducted to examine the relationships among stress and disordered eating variables.

**Results:** Descriptive analyses of the pilot data showed that reported stress levels in this sample of young women were particularly high. It also appeared that the prevalence of clinical eating disorders in this sample was quite small, although infrequent episodes of disordered eating (e.g., binge eating, vomiting after eating) were somewhat more commonly reported.

Results of correlation analyses showed that, despite several correlations being significant, overall there were very few strong correlations between any of the variables examined. In general, then, the expected relationships between psychological stress and disordered eating were not observed. This contradicts many previous findings and there are several possible reasons for this:

- a) The questions/assessment instruments used were not ideal. These have been/will be modified in follow-up studies.
- b) The relationships among these factors may not be the same in Australian women as in American samples. If so, this raises several questions - if young Australian women do not turn to disordered eating when stressed, what do they do? Alternatively if disordered eating does not lead to psychological stress in Australian women, what effects does it have?
- c) The lack of significant relationships may have resulted from the use of an unselected community sample. There was a seemingly low prevalence of disordered eating in this sample, and thus it is planned to use a targeted approach in the future follow-up study; e.g., identify from a community sample, women scoring high on disordered eating measures, and comparing to control groups of women scoring low on these measures.

## 2. Focus Groups

**Design:** It is intended that several focus groups will be conducted to examine in a qualitative, exploratory way, the experiences of young women in relation to stress, coping and eating behaviours. Focus groups are methodologically useful when examining complex behaviours and motivations, and it is anticipated that they will be useful in following up the pilot substudy, pursuing some of the unexpected results obtained in analyses of the pilot data. It is planned to conduct focus groups with young women who have had some form of eating disorder, and with women who have never had an eating disorder, so that the experiences of stress, coping and eating patterns, and the links among these, can be compared across these two groups.

As a general introduction to the first focus group discussion, questions on stressful events and situations were posed. Effects of, and responses to, stress were also examined, and a question on coping mechanisms was included. The issue of major

research interest in the focus group was the possible link between stress, coping and eating and/or weight pathology. To investigate this issue, general questions on attitudes towards eating, dieting, body weight/shape and body image were raised. Finally, a question asking directly about any links between stress and eating behaviours was posed.

**Aims:** It is expected that themes raised in the focus group discussion will help identify possible reasons for the unanticipated results obtained in the pilot substudy, specifically the lack of any links between stress and eating behaviours suggested by the pilot results. The groups also offer the opportunity to explore coping strategies used by young women in response to stress, and the possible role of these in the hypothesised stress and eating/weight relationship. Should there be evidence of a relationship among these factors, it should be possible to explore possible mechanisms governing such a relationship and to generate hypotheses to be followed up in further quantitative testing.

At present only one focus group (women without an eating disorder) has been conducted; the second group is currently being organised. Seven women, aged between 18 and 22 years, took part in the initial focus group.

**Results:** At the completion of the focus group, a descriptive analysis of transcribed responses was conducted. Responses illustrating several main themes (stressful events; coping mechanisms; eating behaviours; and the link between stress and eating) were examined. The women mentioned a broad range of events which they found stressful, including both daily hassle types of events and major life events. Frequently used coping strategies which were reported included talking to friends/family and exercising. This finding also appeared to be borne out in the quantitative data collected in the baseline WHA survey. In response to a question on coping strategies used to deal with stress, for example, approximately 43% of the young women who completed the baseline survey reported that they would talk to a good friend in order to cope with stress most, or all, of the time. While several women in the focus group mentioned using other consumptive behaviours (e.g., drinking, smoking) to cope with stress, none suggested that they regularly changed their eating behaviours to cope. When asked directly about whether there was a link between stress and eating problems, overall the women did not discuss this topic in a lot of depth. Several reported some changes to their eating patterns under stress, but these appeared to be relatively minor or infrequent and not a major focus or disruption in their lives. In general there appeared little evidence from this discussion that stress results in disordered eating in this group of young women. While this was not altogether surprising, given that none of the women had ever had an eating disorder, these women had experienced some major stresses in their lives, so the question of why stress appears to contribute to eating problems in some women but not others, remains unanswered. The planned comparison focus groups, with women with an eating disorder, may shed some light on this.

### **3. Cross-sectional analysis of baseline WHA data**

**Design:** This phase of the study involved an analysis of baseline data collected by WHA for the entire sample of young women (n=14,815), to examine whether there was a relationship between stress and disordered eating in a cross-sectional sense. It was hypothesised that life events stress and perceived stress would be cross-sectionally related to disordered eating symptoms. A further aim was to examine and compare various psychological and other characteristics of women who report being stressed and

have an eating disorder, with women who report being stressed but who do not have an eating disorder. This will help to identify factors which are possibly important in etiology. Body weight, shape dissatisfaction and coping strategies were two factors which are thought to be relevant to this aim.

As this phase of the substudy is still in progress, results will not be reported here.

#### **4. Longitudinal follow-up study**

**Design:** This phase of the study will involve further follow-up data collection, targeting particular groups of women from the WHA young cohort. Approximately 500 women, whose baseline survey responses indicated the presence of one or more disordered eating behaviours, and 500 “control” women who reported never having engaged in disordered eating behaviours, will comprise the subject group for this phase of the study. These women will be sent a follow-up questionnaire assessing life events and perceived stress, coping, depression, and disordered eating behaviours and attitudes. While most of these were assessed in the baseline WHA survey, this follow-up questionnaire seeks more information about these factors, and uses established, psychometrically sound assessment instruments to measure these. A second, similar questionnaire will be sent out six months after the first. This longitudinal follow-up will enable an investigation of these factors, and the relationships among them, over time, addressing such questions as: Does disordered eating persist over time? Does it develop into more severe conditions? How are these changes related to stress? What other factors (depression, body dissatisfaction, coping) are associated with fluctuations in disordered eating behaviours? Does stress lead to disordered eating, or vice versa? Answers to such questions can thus help clarify the role of psychological stress and coping strategies in the development of disordered eating in young women.

This phase of the study is currently still in planning stages. Surveys will be posted in June this year, and results of the first survey will be available by October 1997.

#### **4.4 THE USE AND EFFECTIVENESS OF LEGAL PROTECTION AS A SECONDARY PREVENTION STRATEGY TO REDUCE FREQUENCY AND SEVERITY OF REPEAT DOMESTIC VIOLENCE IN WOMEN'S LIVES**

*PhD candidate:* Margrette Young

*Supervisors:* Professor Annette Dobson, Dr. Julie Byles

##### **AIM**

The main aim of this study is to inform policy and practice on the effectiveness of legal protection and other factors in preventing repeated partner violence in young women's lives. The research is a longitudinal study of changes in partner violence following legal protection compared to changes in partner violence in a comparison group of women without legal protection, in a large national sample of young Australian women.

##### **BACKGROUND**

Research in this field is in its infancy; for example, the first national survey in Australia on the violence women experience was published in December 1996 (ABS). Data from the ABS survey is sufficient only to give a broad cross-sectional description of the extent of the problem and some associated factors.

Partner violence is increasingly reported to police and legal protection orders are increasingly sought and granted. Despite this, there are apparently no empirical data in Australia to guide policy and practice on the extent to which protection orders and reporting to police are effective in preventing violence by partners. There have been no studies in Australia or overseas on whether there is a reduction in violence following legal protection (where legal protection includes protection orders, reporting violence to police or arrest) (Egger & Stubbs, 1993).

##### **DESIGN**

The study is a longitudinal study over 12 months of a large sample of 18-22 year old women, drawn from the Women's Health Australia baseline survey sample. There are 2 components to the study - a cross-sectional baseline survey and a longitudinal survey 12 months later. The cross-sectional survey will provide descriptive baseline data on characteristics of violence and associated social and health factors. The follow-up survey will provide 12 month longitudinal data on the 'natural' history of partner violence which will enable us to study changes in violence over time following legal protection in comparison to other strategies women use to prevent repeated violence. The study will look at factors which differentiate women who seek legal protection from those who don't.

## **METHODOLOGY**

Existing tools will be used in the questionnaire where possible. The outcome and study variables will be measured by victim self-report using computerised telephone interview with methodology and items based on the 1993 Canadian Violence Against Women survey (to which recent cross-sectional surveys in Australia have referred) (Ferrante et al., 1996), and taking into account relevant revisions made in the ABS survey.

Sampling frame: 1770 young women aged 18-22 years who answered 'yes' to the question "Have you ever been in a violent relationship with a partner/spouse" in the main WHA survey

Entry criterion: report of physical violence (as defined below) by partner or ex-partner (as defined below)

Time frame: data collected at baseline and 12 month follow-up.

The definition of physical violence will be physical assault or physical force intending to hurt, measured operationally using items from the 1993 Canadian survey. The definition will exclude emotional or sexual abuse. The definition of partner will be congruent with the definition of the Centre for Disease Control which includes emotionally intimate relationships at the time of or before the violence (e.g. legal marriage, defacto, boyfriend). Threats of physical assault will be measured separately in case abusive partners resort to threats and intimidation as a replacement for physical violence in the period after legal protection.

### **Variables**

The independent variable is legal protection by type (arrest, protection order, report to police).

The main outcome or dependent variable is physical violence by partner or ex-partner, measured by victim self-report. Violence will be categorised as 'minor' violence (e.g. pushing, shoving) and 'serious' violence (e.g. choking, punching, weapons) to provide an ordinal measure of 'severity' of violence..

Specific outcome measures: presence or absence of physical violence by partner;  
frequency of physical violence, separated into minor and serious violence;  
injury (defined from responses to questions about type of injury as used by ABS survey).

Other study variables: The research will also assess factors which may modify the outcome. Such variables include baseline level of violence, duration of relationship at baseline, marital status or type of relationship, socio-economic status and employment, dependents and health.

Multivariate analysis will be used to control for potential confounding or interaction between the outcome measures, independent variables and other factors such as those above.

## **PROGRESS**

1. Substantial review of the literature.
2. Detailed design and methodology for the study has been developed.
3. Sample selection has been determined.
4. Analysis of the data relevant to violence from the baseline survey of the Australian Longitudinal Survey of Women's Health is underway.
5. An abstract on violence for presentation to the 29<sup>th</sup> Public Health Association conference in October has been sent to the Conference Secretariat. The abstract - 'A Health Perspective on Violence' - is based on analysis of ALSWH data.
6. A grant application for additional funds to support the study on the effectiveness of legal protection in the prevention of repeat domestic violence has been successful. (Criminology Research Council).
7. The questionnaire for the study is currently being developed.
8. Margrette Young has established contacts with relevant policy and management personnel and researchers in the field. She attended the Australian Institute of Criminology 1997 conference which included a session on violence and the 1996 ABS survey on Women's Safety.

### **4.5 THE HEALTH OF OLDER WOMEN AS WIDOWS**

*Investigators:* Susan Feldman & Julie Byles

#### **BACKGROUND**

As part of Women's Health Australia, a sub-study of the health needs and services use patterns of older widowed women (now) aged between 70 and 75 years will be undertaken in July 1997 in collaboration with the Alma Unit on Ageing at the University of Melbourne. Earlier qualitative research conducted by the Alma unit (the Older Women as Widows Project) reveals that the needs and expectations of older widowed women are not being adequately addressed by researchers, policy makers, or through health and community service providers.

For many people, older age is a time of great change and adjustment. For women, who have longer life expectancy than men (Australian Institute of Health and Welfare, 1996), older age can often mean change in marital status: from married to widowed. The 1991 census showed that on average Australian women are living up to 8 years longer than their male counterparts and that 80% of widowed persons were women. The Census also revealed that 73% of women aged 85 years and over were widowed (Australian Bureau of Statistics, 1994).

The social consequences of this change in status are likely to be considerable, and yet often overshadowed in health and social research. Much research has focussed on bereavement (Bowling, 1988; Lund 1989; Mendes de Leon, Kasl & Jacobs, 1994; Parkes, 1970; Prigerson et al., 1995;) with little emphasis on the broader needs of these women, nor their longer term adaptation to the new demands and challenges in their lives.

Preliminary analysis of the comments women added to the baseline survey revealed that health, structural problems, relationships, social activities and maintaining a positive attitude to life are of prime importance to these older widowed women. Further analysis of the data also showed differing needs and concerns for women who have been widowed in the short-term (ie. Less than two years) to those of longer term widows. However, both short and long term widows reported stress-related problems such as insomnia, depression and anxiety. Both groups also describe experience of enormous stress in relation to their new responsibilities of managing personal finances and coping with financial hardship. The data showed that diminished income impacts significantly on the health of both groups of widows with notable drops in private health insurance cover. The data also revealed that the women face problems gaining access to quality community support services.

In July 1997, a detailed sub-study on the health needs and service use patterns of women widowed within the past 2 years will be undertaken. This sub-study will provide critical information for planning and designing services for this substantial and increasing sector of the Australian population.

## **AIMS**

The sub-study has the following aims:

1. To gather national data that will enhance the understanding of the key factors that determine the quality of life and health needs of an increasingly dominant social group in Australia
2. To gain a better understanding of the key changes that confront many older widows within the community, living outside of care.
3. To assess how older women negotiate this “normal” transition stage of life and understand the key factor that enhance or impede the process of change.
4. To gather data that has national applicability and is in line with national Women’s Health Policy.
5. To undertake research that has been informed by the opinions of older women and which takes account of older women’s experiences.

Specific research questions:

1. What do recently widowed older women perceive to be the key factors and changes in their lives (including physical, mental, social and structural) following the death of their spouse?
2. What strategies do these older widows living independently in the community use to maintain their health and well being?
3. What do women see as the main role for medical and health (and other) professionals in helping them adapt following the death of their spouse (expectations for care), and how do they rate the care they received (satisfaction)?
4. Do women feel their self-image has changed following the death of their spouse and how do they define themselves now?

## **METHOD**

From the baseline questionnaire responses, 534 women who reported that their husband had died within the preceding 12 months will be surveyed. A modified mail-survey protocol (Dillman, 1978) will be applied including a postcard thank you/ reminder after one week and a replacement package after three weeks.

Women will be asked to complete and return a 51-item questionnaire, developed by Susan Feldman at the Alma Unit. The questionnaire will seek quantitative data on the proportion of women with particular needs and experiences related to health, family and social relationships, and economic and structural issues. In addition, the questionnaire includes several open questions to allow more qualitative data to be collected in a systematic fashion.

Data will be analysed both quantitatively (estimates of proportions and confidence intervals, and assessment of relative risk and adjusted odds ratios for key variables) and qualitatively, allowing a deeper and broader understanding of the data than might be achieved using either approach alone.

## **PROGRESS**

Approval to conduct the study has been granted by the University of Newcastle Human Research Ethics Committee. Following this approval, the questionnaire was pilot-tested with older widows who had previously participated in research conducted by the Alma Unit. These women provided useful feedback on the questionnaire and verified its acceptability appropriateness.

Selected participants from the older cohort of Women's Health Australia will be sent questionnaires in July 1997. Preliminary data from this sub-study should be available for inclusion in the December 1997 report.

### **4.6 CONTRACEPTIVE CHOICE IN YOUNG WOMEN**

*Honours Student:* Stefani Strazzari

*Supervisor:* Professor Lois Bryson (Dr Deidre Wicks) & Dr Wendy Brown (stage one)

## **AIM**

Young women today were born into an era when the oral contraceptive pill had become the predominant form of birth control. The overall aim of the report is to explore how young women perceive their contraceptive choices, particularly in an environment where "safe sex" has taken on a two-fold meaning. This overall aim will be investigated in three stages:

**Stage One:**

1. Data on contraception and prevention of sexually transmitted diseases (STD's) have been extracted from the baseline survey (young cohort).
2. The relationships between contraceptive choice and relationship status, age, ethnicity, occupation and education, and contraceptive choice have been explored.

**Stage Two:**

1. 90 women living in the Hunter Region have been randomly selected from the young cohort for more in-depth telephone interviews about contraceptive choice. The sample includes women who are single, in a defacto heterosexual relationship or married. Each of those interviewed currently uses: the oral contraceptive pill only; condoms only; or both oral contraceptive pill and condoms.
2. Issues to be raised during the interviews will include: how and why do young women make their choice and how satisfied they are with that choice; what sources of information have young women found useful for contraception; why do young women choose particular forms of contraception; how satisfied are young women with the available contraceptive choices; how concerned are young women about unwanted pregnancy and STDs; how much does their partner's attitudes influence their own contraceptive choice?

**Stage Three:**

In-depth interviews will be conducted with six women selected from Stage Two (two women from each of the three groups). Their individual stories will provide more understanding of how contraceptive decisions are related to the everyday lived experiences of young women.

**DESIGN**

The quantitative stage of this study involves analysis of data in the context of previous studies which indicate that the oral contraceptive pill has been remarkably popular in Australia (Bracher & Santow, 1992; Lavis, 1975; Siedlecky, 1979). More contemporary studies suggest that the dual concerns of becoming pregnant and contracting STDs may affect contraceptive use (Browne & Minichiello, 1994; Richardson, 1996).

The quantitative/qualitative approach of stage two will explore more fully the connections between birth control and fears of STDs. Stage three involves in-depth unstructured interviews with six young women selected from stage two. Together these methods will provide insight into young women's views and experiences. This research therefore attempts to engage with feminist debates and research concerned with listening to young women's understandings and own interpretation of their lives (Buchanan, 1993; Thomson & Holland, 1994).

## **PROGRESS TO DATE**

Stage one of the research is complete and the results are being prepared for publication (Strazzari, Bryson & Brown, submitted 1997). Stage two is currently in progress with an initially high response rate. These interviews will help to explore the finding from stage one that between the ages of 18 and 23 there is much movement in young women's lives in terms of jobs, relationships and residence, which may impact on changes in choice of contraception during this period.

### **4.7 SOCIAL SUPPORT, HEALTH STATUS AND HEALTH CARE UTILISATION IN WOMEN AGED 70-74.**

*PhD candidate:* Brendan Goodger

*Supervisor:* Dr Julie Byles

## **BACKGROUND**

Overseas research has shown that social support is an important factor in the health outcomes of older women. A large number of longitudinal and cross sectional studies have noted that older women with low social support have an increased risk of premature death and institutionalisation, physical and psychological morbidity and an increased use of hospital and community services.

Australian research into social support has been limited by measurement difficulties and a reliance on cross sectional research designs. Such research limits an examination of the impact of low social support and risk factors leading to its development. Social support as measured by the 11 item Duke Social Support Index (DSSI) has been shown overseas to be predictive of health care utilisation. This research builds on previous work which just been completed by Dr Byles and Mr Goodger and involved validation of the 11 item Duke Social Support Index and qualitative interviews with older people in receipt of high and low social support.

## **AIMS**

This substudy has three main aims:

1. To assist in identifying the prevalence and predictors of social support amongst older women;
2. To assess the impact of low social support on older women's health and the use of health services;
3. To document the distribution of risk factors contributing to low social support experienced by women living in urban, rural and remote areas of Australia.

## **DESIGN**

To examine the impact of low social support on health status and health care utilisation, a sample of 500 older women will be randomly selected from the lower quartile of the DSSI in the baseline survey. To identify risk factors which may lead to the onset of low social support a further sample of 500 women who have high social support will be randomly selected from the remaining three quartiles.

The total sample of 1000 older women will be surveyed in 1997 and 1998 and will receive a condensed version of the original WHA questionnaire. This condensed version only contains questions relevant to assessing health status and health care utilisation. To elicit qualitative data and to allow participants the opportunity to expand on their answers the questionnaire will contain some open ended questions. Those who do not respond initially will be telephoned to encourage participation and to document reasons for non response.

## **PROGRESS TO DATE**

Approval to conduct the study has been granted by the University of Newcastle Human Research Ethics Committee. The condensed version of the questionnaire has been developed and its pretesting will be finished in the next three weeks. The mail out for this substudy will occur in July 1997. Preliminary data from this substudy should be available in November and will be included in the December 1997 report.

### **4.8 EXPERIENCES OF WOMEN (AGED 45-49) SEEKING HELP FOR PSYCHOLOGICAL DISTRESS**

*PhD candidate:* Sue Outram

*Supervisor:* Dr Jill Cockburn & Associate Professor Margot Schofield

#### **AIMS**

1. To describe women's help seeking for psychological distress;
2. To explore the experiences of these women in seeking help for their psychological distress;
3. To explore barriers to seeking help from the formal sector.

#### **BACKGROUND**

The high rate of mental illness/psychological disorder in the Australian community is considered to be a health problem of national significance. Some studies show that women have up to three times the reported rate of minor psychiatric disturbance of men. Recent reports have documented a lack of information about mental health and illness in the Australian community upon which to make policy decisions. Data from overseas studies are often inappropriately used to extrapolate to Australian populations where significant cultural and health service differences exist. There are no published Australian studies in adult populations which describe help seeking for psychological distress. It is important that help seeking pathways in community populations (as against

clinical populations) are better understood in order to provide more effective and appropriate services. This includes the significance of psychological distress in women's lives, the expectations of people seeking help from formal networks such as medical practitioners and psychologists and their satisfaction with this help. It has been assumed that medical practitioners are the best source of help but reports from some patients would disagree. There is also evidence that that some GPs are not comfortable with psychological problems and prefer to treat physical illness. This study will make a contribution to understanding mental health and help seeking pathways in women and will provide data on which to base further larger scale studies through the Australian Longitudinal Study of Women's Health.

## **DESIGN**

The design is a cross sectional study of a sample of mid aged women drawn from the Women's Health Australia base line survey.

**Methodology:** Semi structured questionnaire administered by telephone survey.

**Sample :** Four hundred (400) women aged 45 - 49 who scored equal to or less than 52 on the Mental Health Index of the SF-36 in the base line study and who live in NSW were randomly selected. The women were sent a letter outlining the research and asking them to take part in a telephone interview.

The majority of the interviews were carried out by the investigator, assisted by two part time trained interviewers with extensive interviewing experience. These women were trained in delivering the semi-structured telephone interview and in support and referral for women who may need further assistance.

**The questionnaire:** Questions about the following areas were included in the questionnaire.

In relation to the most recent distressing time in the past year, information was collected about the following:

- Causes of distress;
- Ways of coping;
- Informal sources of help (partner, friends, family);
- Formal sources of help (GP, psychiatrist, counsellors, psychologists, social/welfare workers, natural therapists, self help groups);
- The type of help given (practical help, medications, counselling, sharing);
- Perceived effectiveness of this help;
- Barriers to seeking help;
- Confidence in their General Practitioner in relation to mental health/emotional difficulties;
- Childhood risk factors for depression (death of parents or other separation as a child, physical and sexual abuse);
- Individual women's perceived strengths in coping with life's difficulties.

Other relevant variables (geographical location, education, occupation, marital status, children living at home) for this sample obtained from the base line survey will be used.

### **Qualitative data**

The planned indepth qualitative second phase of the study will not proceed as the telephone interviews (often 40 minutes to one hour in duration) were able to yield sufficient qualitative data on the women's attitudes and beliefs about seeking help.

As would be expected in a study following women's stories of such an intimate part of their lives more information was obtained than could be directly entered on the questionnaire. Beliefs and attitudes about key areas of 'help seeking' such as using psychotropic medications, getting professional help, as well as experiences in accessing this help were explored. Where possible the woman's comments were written verbatim. This qualitative data will be coded and entered into a data package for analysis.

Eighty four of these women had written comments on their baseline questionnaire and relevant comments will be incorporated into this study.

### **PROGRESS**

Three hundred and twenty seven interviews have been completed. The response from the women contacted has been positive. As would be expected, some women found the prospect of talking to someone about personal issues uncomfortable. Fifteen (15) women declined to take part, the usual reason being that they did not want to talk about their personal problems.

The main difficulties in interviewing the anticipated number of participants arose from silent telephone numbers, lack of English proficiency and changes in address and/or telephone numbers since the baseline survey. Five women had moved out of NSW (all to Queensland therefore not lost to the larger study but ineligible for this sub-study). After excluding ineligible women there was a 95% response rate.

The data collection was completed December 1996 and entered into a computer data base in February 1997. Ms Outram took leave from study in February (due to work pressures) and will resume in July. The analysis will be completed and papers and a draft thesis prepared by February 1998.

Two papers presenting research findings from this study have been submitted for conferences in September (29th Public Health Association, Melbourne) and October (First National Conference on Women's Health Promotion, Newcastle) 1997.

## 4.9 WEIGHT CHANGE AT MENOPAUSE

*PhD candidate:* Lauren Williams

*Supervisor:* Dr Wendy Brown

### BACKGROUND

During 1996, 14,200 middle aged participants in the Australian Longitudinal Study of Women's Health completed a baseline survey covering a wide range of health and social issues. This substudy will use quantitative and qualitative survey techniques to follow a nested cohort of ALSWH participants who progress through natural menopause between 1996 and 1998, to determine relationships between weight change at menopause and dietary intake, physical activity, weight control strategies, psychosocial and environmental factors. Improved understanding of the determinants of weight change at this life stage will be used to inform the development of strategies for the prevention of weight gain, overweight and obesity (and associated cardiovascular problems) in women.

### AIMS

1. To explore the distribution of Body Mass Index (BMI) and its relationship with other cardiovascular risk factors and related problems according to menopausal status [using the baseline (cross-sectional) 1996 data from the Australian Longitudinal Study on Women's Health (ALSWH), N=14,200 women aged 45-49 years].
2. To identify women who experience natural menopause between 1996 and the first ALSWH follow up survey in 1998, and compare body weight change and related cardiovascular risk factors with those in women whose menopausal status does not change during the same period or those who take Hormone Replacement Therapy (HRT) continuously (N=1,500-3,000 per group).
3. To identify the behavioural and/or environmental factors which put women at risk of weight gain over the menopausal years, in order to inform the development of population based prevention strategies.

### Hypotheses:

1. ALSWH participants who experience natural menopause between 1996 and 1998 will have a greater mean weight gain than those whose menopausal status remains unchanged (even after adjustment for age, cigarette smoking, socio-economic and other factors) (Boyle et al., 1994). (Women taking HRT continuously during this period to be excluded).
2. Data gathered by qualitative inquiry are usually used to generate hypotheses rather than test them. Specific questions to be explored with the women experiencing natural menopause during the study period are as follows: how do women who lose/gain weight explain these changes? What motivates them to control/not control their weight? What roles do they perceive dieting, eating and activity have played in their weight gain/loss? What social, economic and environmental factors influence these behaviours?

## **SIGNIFICANCE**

The NH&MRC have identified women in the menopausal years (45-55) as a key target group for the prevention of overweight and obesity in their public health strategy *Acting on Australia's Weight*. A detailed understanding of factors influencing weight gain during this life stage has the potential to inform large scale primary prevention programs to halt the increasing prevalence of overweight and obesity, and associated heart disease and other problems, in women after middle age.

## **RESEARCH PLAN**

The research will be conducted in three stages over a two year period, using both quantitative and qualitative methodologies. The quantitative component will measure the extent of the problem of weight gain at menopause, and contributing behaviours, while the qualitative research will explore the reasons for these behaviours.

### **Preliminary Stage: analysis of 1996 survey data on relationship between weight and menopause.**

Statistical analysis of the relationships between the distribution of Body Mass Index (BMI), with other cardiovascular risk factors (hypertension, diabetes, smoking) and related problems, according to menopausal status, using the baseline (cross-sectional) 1996 data from WHA, N=14,200 women aged 45-49 years. Data from women who take hormone replacement therapy (HRT) and/or who have had a hysterectomy will be analysed separately.

### **Stage One: Comparison of 1996 and 1998 survey data in relation to weight and menopause.**

Women who experience natural menopause between 1996 and the first WHA follow up survey in 1998 will be identified as being 'peri-menopausal'. Changes in body weight and related cardiovascular risk factors for this group will be compared with those in women whose menopausal status does not change during the same period (either pre-menopausal or post-menopausal). Women who take HRT continuously between the surveys will be analysed as a separate group, and excluded from the three previous groups. The estimated number in each of the four groups: pre, peri, post menopausal and HRT, is between 1,500 and 3,000 women. Women who have had a hysterectomy or bilateral oophorectomy, and who are not in the 'HRT' group will be excluded. The peri-menopausal group will be further studied in stage two.

### **Stage Two: Nested cohort study of women in the menopause transition.**

The peri-menopausal group will be sub-divided into four groups on the basis of weight change during the two year period: those whose weight decreased, remained stable, increased by less than 5kg or increased by more than 5kg. The number of women in each of these groups is estimated, on the basis of the 1996 WHA data, to be between 500 and 700 women. A questionnaire based on prevalidated instruments which measure dietary intake (food frequency questionnaire), exercise (frequency questionnaire), dieting (WHA pilot questionnaire) and other lifestyle habits will be developed, piloted

and distributed to all women in the peri-menopausal group. These behaviours will be compared among the 4 groups defined by weight change using analysis of variance and covariance (to take account of likely confounders such as cigarette smoking, age and socio-economic status).

### **Stage Three: qualitative study of values and beliefs about weight gain and menopause.**

A subsample of women from stage 2 will be selected from one rural and one metropolitan location for participation in focus groups. Six focus groups will be conducted in each location. Discussion will focus on menopause-related weight change and weight control experiences of the women themselves in the context of their domestic, work and leisure time roles. Separate focus groups will be held for women who have gained weight and women who have lost weight, or whose weight has remained stable. The questions will focus on perceived weight changes during menopause and reasons for this change. Specifically, the women will be asked what motivates them to control/not control their weight, and whether they perceive weight gain to be a health risk. They will also be asked to describe behaviours which have helped/hindered in controlling their weight, and to discuss social and environmental factors which have been facilitators/barriers to these behaviours. Transcripts will be coded and analysed according to themes arising from data.

### **PROGRESS**

This is a new sub-study. Preliminary analysis of the baseline data and allocation of women to 'menopause' groups (hysterectomy, HRT, pre-menopause, peri-menopause and post-menopause) has been completed. Work on the preliminary stage of this sub-study will begin in July 1997.

## **4.10 YOUNG AUSTRALIAN WOMEN: THEIR ASPIRATIONS RELATING TO WORK, CAREER, AND RELATIONSHIPS**

*Investigator:* Deidre Wicks

### **AIM**

The broad aim of this research is to produce new data which will increase our understanding of the interactions between gender, self identity, aspirations regarding paid work and relationships and the role of situational factors in the formation and maintenance of aspirations, on women's health. This broad aim will be achieved through successfully meeting four separate but interrelated aims, which are as follows:

1. To elicit information on the aspirations of the young women who represent the young cohort of the Australian Longitudinal Study on Women's Health (ALSWH) (approximately 14,000 women between the ages of 18-22 years), and, in particular, to determine their aspirations in relation to:

- work/career choice;
  - full time, part time or no paid work;
  - further educational qualifications;
  - relationships, marriage, children (how many).
2. To ascertain the strength of the connection between aspirations, socio-economic level, educational attainment and health.
  3. To explore some key issues surrounding the aspiration choices made by a sub-sample of 100 women, including:
    - reasons for choice (in relation to gender and self-identity);
    - their expectations regarding work and relationships;
    - extent of planning (or lack of) involved in their work choices;
    - degree of optimism/pessimism regarding realisation of their aspirations;
    - extent of their self esteem.
  4. To establish baseline data for a follow up study in four years time and thereafter at four yearly intervals, which will allow exploration of the impact of these factors on women's health.

## **DESIGN**

Stage one of the research consists of the retrieval and analysis of the ALSWH computer file section on "aspirations". The responses have been analysed in relation to current sociological debates on women's participation in the workforce and their aspirations regarding work, career and family life. These debates centre on feminists' historical focus on the structural impediments to women's full participation in the workforce (Beechy & Perkins, 1987; Burton, 1991; Cockburn, 1991) and the contrary view that the sexual division of labour is simply the outcome of women's acceptance of differentiated sex roles and their preference for either part-time work or full time homemaking (Becker, 1991; Hakim, 1995). The completion of the first stage of the research plan for this project will provide new, quantitative information from a large cohort which will add significantly to our knowledge of these aspects of women's lives.

**Stage two** of the research consists of semi-structured interviews with a random sample of 100 of the respondents for an in-depth exploration of the issues covered in the questionnaire. The plan is to re-interview the individuals in this sample every four years so that their aspirations and the realisation of aspirations can be followed over different life stages, to see if these factors impact significantly on health outcomes. A semi-structured interview format has been chosen as it is the most appropriate method for eliciting data which is both comprehensive and detailed (Lofland & Lofland, 1984). The qualitative data will add depth to the quantitative data generated in stage one. There is also the potential to broaden the debate by introducing hitherto unexplored evidence on the meaning of work and relationships to gender identity and self esteem (Connell, 1987, 1995; Pringle, 1994). As well as the information gathered from what is essentially a cross-sectional study, this information will also provide baseline information on aspirations for an ongoing longitudinal study which will follow this group of individuals over a twenty year period.

## **Methods**

The methods to be utilised include both quantitative and qualitative data gathering and analysis. They are:

1. Data retrieval of ALSWH computer file section on "aspirations";
2. Analysis and correlation of work/career aspirations with socio-economic and education levels of respondents (and parents) and health status;
3. Use (and if necessary adapt) a suitable computer program (Nudist, Ethnograph) for the retrieval of the qualitative data;
4. Semi-structured interview with a sub-sample of cohort (100) to explore issues outlined above.

## **PROGRESS**

Stage 1 of the research is near completion. The data for the aspirations of the young women have been analysed and frequencies obtained in regard to work, relationships, and children. In addition, the answers provided by respondents in relation to their work or career of choice have been retrieved and classified according to the widely used ASCO occupational classification system. This will enable comparisons of the projected aspirations of our cohort with current occupational segregation by gender, as well as comparisons with the occupations of the middle aged cohort from the ALSWH. Cross tabulation of aspirations with social class will be possible following the first follow-up survey, when information about the occupations of the young woman's parents will be obtained. We are attempting to substitute areas of social disadvantage/advantage as markers for social class so that it will be possible to explore this issue before the follow-up survey. Cross tabulation of aspirations with ethnicity is currently underway. The results of stage one will be presented at a National Conference on Unemployment (Adelaide) in June, 1997. Stage two of the study will commence in July.

## **5. RESEARCH ACTIVITIES**

### **5.1 COLLABORATION WITH OTHER RESEARCH CENTRES**

The Principal Investigators on ALSWH have adopted a policy that encourages other researchers to collaborate on specific analyses or sub-studies. The goal is to broaden the expertise that is brought to bear on the issues under investigation, to maximise the benefit for women and women's health. To facilitate this collaboration a standard memorandum of understanding has been developed (see Appendix 4). Two examples of this collaborative research model are provided below. Negotiations are underway to involve other researchers in a similar way.

#### **5.1.1 *Alma Unit On Women And Ageing, University Of Melbourne* *Susan Feldman (Director) Older Australian Women as Widows***

The Alma Unit on Women and Ageing, based at the University of Melbourne's new multi-disciplinary Centre for the Study of Health and Society, is a unique research and teaching unit which focuses on the health and well-being of women over the age of 60 years. During 1996, the Alma Unit's research program focused on the investigation of the factors that affect the health and well being of older widowed women over the age of 60 years. Qualitative research conducted by the unit (the Older Women as Widows Project) reveals that the needs and expectations of older widowed women are not being adequately addressed by researchers, policy makers, or through health and community service providers.

Women's Health Australia presents a key opportunity for the needs and expectations of recently widowed older women to be explored more thoroughly. To this end, Susan Feldman (Director of the Alma Unit) is working collaboratively with Julie Byles (Women's Health Australia). Their research has four main phases: 1) thematic analysis of the qualitative comments provided on the baseline questionnaire (see Section 2.3 for a preliminary report); 2) statistical analysis of baseline (cross-sectional data) to identify health and other variables associated with being widowed, and the differences between women widowed within twelve months preceding the questionnaire and those widowed for a longer period of time (see Section 5.3.3 for an abstract); 3) a sub-survey of women who were widowed within twelve months prior to the baseline questionnaire to explore the needs, expectation and experiences of these women (see Section 4.5 for research proposal and progress report); 4) statistical analysis of longitudinal data to occur after the first follow-up of the full cohort of older women (planned for 2000).

Collaboration between the two chief investigators on these sub-studies has been highly productive and rewarding. The researchers bring complementary expertise (qualitative and quantitative) to bear on an important determinant of women's' emotional, physical and social well being. The resultant research and its findings are likely to have important implications for health policy and for service provision.

**5.1.2 *Turning Point Alcohol and Drug Centre, University of Melbourne***  
***Helen Jonas - Exploration of the associations between alcohol consumption and emotional health in women of different age groups***

Women with more emotional concerns and stress in their lives are more likely to consume alcohol at hazardous/harmful levels, or to have more episodes of “binge” drinking. However, it should also be remembered that many other factors are likely to be associated with alcohol consumption: These include: age; smoking; income; employment status (especially applicable if looking for work); type of occupation; marital status; ethnicity; education; exercise level; weight (under- or over-); prevalent disease; prevalence of “common problems”; number of medications taken per week; self-assessment of physical functioning, general health, vitality, and bodily pain (as measured by the SF-36 questionnaire).

Because these factors are also likely to be related to levels of stress and emotional distress, they have the potential to confound the relationship between harmful levels of alcohol consumption and the prevalence of stress/emotional distress. They may also modify the associations between alcohol consumption and emotional health. Thus, any analyses of the associations between alcohol consumption and stress/emotional distress may need to adjust for a number of these factors. These issues will be explored by Dr Helen Jonas, whose expertise in this area will add significantly to our understanding of the complex relationships between alcohol and health. Dr Jonas has recently submitted an abstract for presentation of a paper at the forthcoming PHA conference in Melbourne

## **5.2 VISITS TO OTHER RESEARCH CENTRES**

BYLES J. Alma Unit on Women and Ageing, University of Melbourne. 13/2 - 14/2/97

BROWN WJ.. Key Centre for Women's Health, University of Melbourne. Met with Lorraine Dennerstein, Janet Guthrie and Wendy Vanselow. 19/3/97.

LEE C. Honorary Research Fellow, Women's Health Research Unit, Department of Psychology, University College London. 10/3 - 10/6/97.

## **5.3 PRESENTATIONS**

### ***5.3.1 Conference and workshop presentations***

BYLES J

Women's Health Australia. *CCEB Distance Learning Residential Program*. University of Newcastle. 26 February 1997.

Epidemiology. *National Breast Cancer Center, Breast Cancer Science and Advocacy Training Workshop, NSW Cancer Council*. Sydney. 17-18 April 1997.

Preventive care for older Australian veterans and war widows Workshop on advice, counselling and referral. *The Central Co-ordinating Committee of the Department of Veterans' Affairs Preventive Care Trial*. Newcastle. 23 April 1997.

#### BROWN W

Subcommittee on Women's Health: Update on the Women's Health Australia project. *AHMAC*. Canberra. March 1997.

The Hunter Women's Health Nurse Pilot Practitioner Project. *NSW College of Nursing/NSW Nurses' Association. National Symposium on the nurse practitioner pilot projects*. Sydney. 28 February 1997.

#### LEE C

Staff seminar, "It's your hormones, dear". Department of Psychology, University of Birmingham. 24 April 1997.

Invited seminar, "Exercise and well-being among middle-aged women". Health Psychology Research Group, Department of Psychology, University of Exeter. 2 May 1997.

#### OUTRAM S

Australian Longitudinal Study on Women's Health. *The Seventh International Congress on Women's Health Issues*. Khon Kaen, Thailand. 5-8 November 1996.

#### **5.3.2 Papers accepted for presentation**

MISHRA G. The Australian Longitudinal Study on Women's Health: Study design. *Regional Conference on Longitudinal Data Analysis*. Columbia, Missouri, USA June 10-14 1997.

##### **Abstract**

The Women's Health Australia project, is a longitudinal study of several cohorts of Australian women, which aims to examine the relationships between biological, psychological, social and lifestyle factors and women's physical and emotional health, and their use of and satisfaction with health care services. This project is designed to track the health of several cohorts of women over a period of up to twenty years. So far we have finished the first stage of recruitment of participants (N=41,578) for the three main cohorts (aged 18-22, 45-49 and 70-74). This paper will discuss the study design, major study themes and progress to date.

SCHOFIELD M, DOBSON A & MISHRA G. Smoking, menstrual problems and early menopause: Women's Health Australia project. *Submitted to 10th World Conference on Tobacco or Health. Aug 24 - 28, 1997. Beijing, China.*

##### **Abstract**

Women's Health Australia is a longitudinal study of young, middle-aged and older Australian women. This paper describes the relationship between smoking status, menstrual problems and early menopause among the middle-aged cohort of 14,200 women aged 45 to 49 years. The sample frame was the national health insurance data

base. Participants were randomly selected, with over-sampling from rural and remote areas and are broadly representative of Australian women in those age groups. Results from the baseline survey show a strong positive relationship between smoking and menstrual problems, and smoking and early menopause. Current smokers were more likely than ex-smokers or never smokers to report having heavier, more changeable, and irregular periods over the past 12 months as well as severe period pain. They were also more likely to report having completed a natural menopause. The findings support previous work suggesting that smoking is associated with higher risk of menstrual problems and early menopause.

SCHOFIELD M, MISHRA G & DOBSON A. Probability of miscarriage among smokers: Women's Health Australia baseline survey. *Submitted to 10th World Conference on Tobacco or Health. Aug 24 - 28, 1997. Beijing, China.*

**Abstract**

Women's Health Australia is a longitudinal study of several cohorts of Australian women. The study aims to examine the relationships between biological, psychological, social and lifestyle factors and women's physical and emotional health over a period of 20 years. This paper presents retrospective self-reported data from the baseline survey on the relationship between smoking and history of miscarriages 14,780 women aged 18-22, and 14,200 women aged 45 to 49 years. The sample frame was the national health insurance data base. Participants were randomly selected, with over-sampling from rural and remote areas and are broadly representative of Australian women in these age groups. There was a strong positive relationship between smoking status and number of reported miscarriages. Three or more miscarriages were reported by 7.4% of current smokers, 5.3% of ex-smokers and 3.7% of never smokers in the middle age group. Among young women, 1 or 2 miscarriages were reported by 6.2% of current smokers, 4.7% of ex-smokers, and 1.4% of never smokers. A positive relationship was also found between number of miscarriages age of starting to smoke and number of cigarettes smoked. The results provide strong evidence of a link between smoking and miscarriages and suggest that new initiatives are needed to prevent smoking among women of childbearing age.

WICKS D & MISHRA G. Young Australian women and their aspirations for work, education and relationships. *National Conference on Unemployment. Adelaide 18-20 June 1997.*

**Abstract**

It is recognised that while women make up over half of tertiary enrolments, this outcome is not reflected in the gender composition of occupational structure, career patterns and pay distribution. There are a number of different explanations for this including a recent contribution from British sociologist Catherine Hakim who identified the main causal factor as women's own lack of career orientation and work commitment. Hakim's contribution has produced a lively debate with all sides acknowledging the lack of, and need for, longitudinal data on women's workforce participation. The present paper investigates data from the first stage of the Women's Health Australia Longitudinal Study which provides a valuable opportunity to inform this debate through an analysis of the aspirations of a large group of young Australian women aged 18-22 years. The investigation will be conducted in relation to young women's aspirations for work, relationships and further education. In this context, the implications for the "Hakim debate" will be discussed. It will be demonstrated in the paper that analysis of the initial

data casts light on debates about women's workforce participation at the same time as establishing baseline data for future research on the work and family patterns of this group of young women. The information will have significance for policy debates in several areas, including those concerned with child care, access to higher education and workforce planning, as well as health.

### **5.3.3 Papers submitted for presentation**

BROWN W & BALL J. Is life a party for young women in Australia? *Australian Council on Health, Physical Education & Recreation Conference. Adelaide September 1997.*

#### **Abstract**

During 1996, baseline data for the Australian Longitudinal Study on Women's Health (now known as the Women's Health Australia or WHA project) were collected from women in three age groups (18 - 23; 45 - 50; 70 - 75). The project aims to explore how changes in biological, psychological, social and lifestyle factors impact over time on women's physical and emotional health. Participants in the study were randomly selected from the HIC/Medicare data base, and represent women from all walks of life, from every State and Territory of Australia. This paper will report baseline findings from the young cohort (N=14600), focusing on lifestyle issues which may impact over time on health outcomes. Descriptive data on self-reported lifestyle variables, as well as causes of, and methods of coping with stress, will be included. One third of the cohort are current smokers (mean ( $\pm$  sd) age of starting smoking,  $15.4 \pm 2.35$  years); 17.4% drink 5 or more drinks at least once a week; 27% use condoms to protect against STD's; 29.2% had a BMI  $<20 \text{ kg/m}^2$  and 40.8% do little or no exercise. Only 1.6% said they were happy with their weight, and more than half the cohort (57%) had (ever) dieted to lose weight. The mean (sd) age when first dieted was  $15.4 \pm 2.50$  years. The most common causes of stress in this group are money, employment and study, and the most common method of coping was talking to a good friend. These cross-sectional data provide insights into the health behaviours of young Australian women, and highlight issues which could be addressed in health education and/or health promotion programs.

BROWN W & MISHRA G. Getting movement on the women's health agenda. *1st National Conference of Women's Health Promotion. Newcastle 7-8 September 1997.*

#### **Abstract**

**Objectives:** (1) To report on the development and use of a short, simple measure for estimating levels of population physical activity. (2) To evaluate the relationship between activity levels and indicators of physical and mental health and well being in women.

**Design:** Cross-sectional data from mail survey to women in three age groups (18-23; 45-50; 74-79), selected randomly from the HIC/Medicare data base.

**Participants:** Women participating in the Australian Longitudinal Study on Women's Health (the Women's Health Australia project) (N= 41500). (Including women from all walks of life in all States and Territories of Australia)

**Results:** Only 23% of the young, 12.1% of the middle and 9.7% of the older women reported activity levels which equate with energy expenditure (EE) of 1200kcal per week. (Current US guidelines suggest EE of 200kcal per day will result in health benefits). Activity levels were positively associated with SF-36 sub-scale scores, and

inversely associated with self reported hypertension, osteoporosis, back pain, tiredness and constipation, particularly in older women.

Conclusions: The data confirm that the majority of Australian women do not have sufficient daily activity to maintain optimal levels of health. This finding supports the call for more attention to movement on the women's health agenda. While the direction of causality cannot be implied from these cross-sectional data, the results suggest that significant health benefits may accrue from activity equivalent to EE of only 600kcal/week. The longitudinal nature of the WHA study will allow testing of this hypothesis in due course.

BRYSON L. Rural women's health, time use and the life cycle. *Rural Australia: Towards 2000 Conference. Charles Sturt University, July 2-4 1997.*

**Abstract**

While the factors affecting women in rural and remote areas are recognised as often different from those which affect women in urban Australia, this factor is not consistently studied, nor are the intricate and varied processes which are involved for women of different ages in 'juggling' their time. Data from the first stage of the Women's Health Australia longitudinal study provide a valuable opportunity to explore the links between these factors and health. Data on health, time use, age and urban/rural/remote location comes from a sample of over 40,000 women in three age groups, 18-22 years, 45-49 and 70-74, randomly drawn from all over Australia, but with deliberate over-representation of women from non-metropolitan areas. Data about actual time use (paid/unpaid work/study, family responsibilities, leisure) and self assessed feelings about time pressures are examined for their links to other health indicators. These include: self-assessed health status, measures of current health (eg symptoms, medical conditions) and health history (eg past illnesses, health services usage). By linking patterns of time use with health data against the background of geographical location, the analysis has the capacity to cast light on social issues which are of specific interest for women residing in rural and remote Australia, and to contribute to policy debates about appropriate responses to the reality of rural/remote women's lives and their health concerns.

BRYSON L. Women's health, time use and the life cycle. *Women as Well: Gender & Health, The Women's Studies Centre. University of Sydney, July 1997.*

**Abstract**

It is well recognised that many women are engaged in intricate processes of 'juggling time', yet there is little research connecting this to health issues. Data from the first stage of the Women's Health Australia longitudinal study provide a valuable opportunity to explore this connection because the three age groups of women, 18-22 years, 45-49 and 70-74 who make up the sample of over 40, 000 women, have contrasting time use patterns. Data about actual time use (paid/unpaid work/study, family responsibilities, leisure) and self assessed feelings about time pressures are examined for their links to other health indicators. These include: self-assessed health status, measures of current health (eg symptoms, medical conditions) and health history (eg past illnesses, health services usage). Linking time use and health data has the capacity to transcend the traditional compartmentalisation of women's lives, typical of so much research. The analysis casts light on immediate health issues at the same time as contributing to other broad theoretical debates, for example that involving researchers such as Hakim in the UK and Probert in Australia about the nature of, and basis for, women's particular patterns of combining family and economic work. The analysis is also central to policy

debates about appropriate responses to the fin de siècle reality of women's lives and their health concerns.

BYLES J, FELDMAN S & MISHRA G. For Richer, for poorer, in sickness and in health: Marital status and older women's health, relationships and financial security. *29th Annual Conference of the Public Health Association. Melbourne 5-8 October 1997.*

**Abstract**

In the baseline survey of the Australian Longitudinal Study on Women's Health, 34.5% of the 12624 women aged 70-74 years were widowed, and 13.5% of these women were widowed within the past 12 months (recent widows). These women have very different needs to other women of the same age.

Results Health: Recent widows were more likely to rate their health as fair or poor (35% vs 26%,  $p < 0.001$ ) and were more likely to report they were stressed about their health than married women (56% vs 46%;  $p < 0.001$ ). Recent widows scored significantly lower than other women (including widowed more than 12 months) on all 8 sub-scales of the SF-36 ( $p < 0.01$ ); and were more likely to be taking medication for 'nerves' (18% vs 12%) and 'sleep' (25% vs 18%) ( $p < 0.01$ ). Relationships: Stress with family relationships was associated with marital status ( $p < 0.001$ ); recent widows being more likely to report such stress (25% vs 21%). Recently widowed women were more likely to be unhappy with the amount of time spent alone than other women (16% vs 8%,  $p < 0.001$ ). However, scores on the Dukes Social Support Instrument (and subscales) did not vary according to marital status and showed generally high levels of support for most women. Financial Security: Women who are widows were more likely to be stressed about money (30% vs 21%,  $p < 0.001$ ) and their living arrangements (13% vs 9%,  $p < 0.001$ ), more likely to report difficulty managing on the income available (32% vs 22%,  $p < 0.001$ ) and less likely to have private health insurance (40% vs 56%;  $p < 0.001$ ) than married women.

Conclusions These findings provide a framework for exploring the short and longer-term needs of women who are widows. More immediately, comments provided by the women provide further insights for the provision of appropriate health care and community support.

BYLES J & Harris M. Screening for Cervical Cancer: Health Care, Isolation and Social Support. *1st National Conference of Women's Health Promotion. Newcastle 7-8 September 1997.*

**Abstract**

Objectives: To test hypothesised associations between cervical cancer screening and health care use, geographical isolation, social roles and social support in middle-aged women.

Design: Cross sectional data from a mail survey to women aged 45-49 years, randomly selected from the HIC/Medicare data base.

Participants: Participants in the Australian Longitudinal Study on Women's Health (the Women's Health Australia project) (N=14200).

Results: As in other studies, women with lower education and occupational status, NESB and ATSI women were least likely to be screened ( $p \leq 0.001$ ). There were also highly significant associations between screening and the number of visits to a local doctor, convenience of location of GP, preference for a female provider and use of oral contraceptives or hormone replacement therapy ( $p \leq 0.001$ ). Post menopausal women were less likely to be screened than other women in this age range ( $p \leq 0.001$ ). While geographical isolation was not significantly associated with screening, social support

was a highly significant factor ( $p \leq 0.001$ ). Conversely, time use was inversely associated with screening: the busiest women were most likely to be screened.

Conclusions: The importance of social support as a facilitator of screening warrants further exploration. Greater insight into this aspect of women's lives may open new avenues for promoting and enabling cervical screening among all women.

CHIARELLI P & BROWN WJ. The prevalence of leaking urine in Australian women. *1st National Conference of Women's Health Promotion. Newcastle 7-8 September 1997.*

**Abstract**

Objectives: Evaluation of the prevalence of urinary incontinence in Australian women.

Design: Retrospective analysis of data from the Australian Longitudinal Study on Women's Health.

Participants: The prevalence of leaking urine (in the last 12 months) was estimated to be 12.8% (CI 12.2-13.3) in the younger group, 36.1% (CI 35.2-37.0) in the middle group and 35% (CI 34.1-35.9) in the older group. Amongst Aboriginal and Torres Strait Islander women, prevalence was higher in the younger women (19.4%; CI 14.83-23.9) and among women reporting English as a second language, prevalence was lower in the middle group (30%; CI 26.7-32.9). Variables which were associated with higher rates of leaking urine included parity, pregnancy or birth within the last year, upper respiratory tract conditions, obesity, constipation, other bowel problems, diabetes and stroke. Women who reported having urine that burns or stings, or ever having had a prolapse, hysterectomy, bilateral oophorectomy or repair of prolapsed vagina, bladder, or bowel, were also more likely to report leaking urine.

Conclusion: Urinary incontinence is common amongst Australian women of all ages. Continence promotion should begin before first pregnancy, and secondary prevention services should be more widely available.

KENARDY J. The health impact of dieting in young Australian women: The Australian Longitudinal Study on Women's Health. *14th World Congress on Psychosomatic Medicine. Cairns 31 August 1997.*

**Abstract**

Dieting is seen as one of the core factors in the development of problematic eating and weight disorders. This study examines the impact of dieting on mental and physical health in a large sample of young Australian women. As part of the Australian Longitudinal Study on Women's Health, 14,810 women aged 18 to 22 years were asked about their dieting and eating history and behaviours, physical and psychological health, weight, and body image. Lifetime prevalence of dieting was 55%, with over 20% reporting having undertaken five or more diets in the last year. More frequent dieting was associated with greater relative body mass (BMI), poorer physical and emotional health, greater likelihood of disordered eating behaviours, and poorer body image. Of more concern was the finding related to age of first diet. More than 11% of the sample reported engaging in their first diet before age 13. These women had a greater risk of disordered eating behaviours, higher BMI, poorer physical and emotional health, and greater usage of the health system than women who started diets later, or who had reportedly never dieted. This has significant implications for public health and preventative programs.

PATTERSON A & MIDDLELINK L. Factors associated with low iron in women of childbearing age. *1st National Conference of Women's Health Promotion. Newcastle 7-8 September 1997.*

## **Abstract**

**Objectives:** To investigate associations between low iron and factors thought to influence its development, and to examine possible health effects of iron deficiency for Australian women.

**Design:** Cross-sectional data from the baseline survey of the Australian Longitudinal Study on Women's Health (ALSWH) (middle cohort: 45-49 years).

**Results:** Women who reported (ever) having had low iron were more likely to report: pregnancies and childbirth ( $p<0.001$ ,  $p<0.001$ ); heavy periods ( $p<0.001$ ); low or high levels of exercise ( $p<0.001$ ); constant tiredness ( $p<0.001$ ) and lower scores on all sub-scales of the SF-36 ( $p<0.001$ ). Women with a history of low iron were less likely to report taking the oral contraceptive pill ( $p<0.005$ ) or drinking alcohol. There was no association between history of low iron and current dieting status ( $p=0.211$ ), or number of diets in the last 12 months ( $p=0.128$ ).

**Conclusion:** While no causality can be implied from these data, the findings highlight those factors which may be important in the development of low iron. Further exploration of these issues will inform the development of health promotion programs for the prevention of low iron in Australian women.

OUTRAM S & SCHOFIELD M. Women: Living well into the 21st Century. *First National Conference on Women's Health Promotion. Newcastle 7-8 September 1997.*

## **Abstract**

The baseline survey of the Australian Longitudinal Study on Women's Health, conducted in 1996, identified a sub-sample of 325 women in New South Wales aged 45-49 years who had high levels of psychological distress as measured by the SF-36. The aim of this sub-study was to determine how many women sought formal help for their distress, to explore the experiences of these women in seeking help for their psychological distress, and to explore reasons for not seeking help. Trained interviewers administered a semi structured interview by telephone. High rates of psychotropic drug use by women have been highlighted in various studies in the past decade. In this study 36% of women said they had taken tablets or medicines to help them cope with a recent episode of psychological distress. Medications included psychotropic drugs, natural products such as evening primrose oil and Hormone Replacement Therapy. This paper will present information about the medications used and will discuss the resistance to medicating feelings expressed by many of the women who were interviewed and the potential this has for promoting women's health and well being.

OUTRAM S & SCHOFIELD M. Psychological distress among mid age women in NSW: help seeking and barriers to seeking help. *29th Annual Conference of the Public Health Association. Melbourne 5-8 October 1997.*

## **Abstract**

The baseline survey of the Australian Longitudinal Study on Women's Health, conducted in 1996, identified a sub sample of 325 women in New South Wales aged 45-49 years who had high levels of psychological distress as measured by the SF-36. The aim of this sub study was to determine how many women sought formal help for their distress, to explore the experiences of these women in seeking help for their psychological distress, and to explore reasons for not seeking help. Trained interviewers administered a semi structured interview by telephone. All but 4.3% of these women affirmed they had been very distressed or very worried in the past year. Fifty one per cent of women reported consulting a general practitioner to get help, 8% a psychiatrist,

17% a counsellor, 11% psychologist and 5% a social worker. The women were asked what had made it difficult or stopped them seeking professional help. This paper will present data on the professionals consulted and the reasons women gave for not seeking help. An important concern for women in small country towns and rural areas was privacy and the fear of lack of confidentiality.

YOUNG M, DOBSON AJ & BYLES JE. A health perspective on violence. *29th Annual Conference of the Public Health Association. Melbourne 5-8 October 1997.*

**Abstract**

Australian and overseas data on violence show that young women are at greatest risk. This study reports cross-sectional data on violence and young women's well-being (using short form general health survey - SF-36).

Method: Self-reported data from postal questionnaires in the baseline surveys of the Australian Longitudinal Study of Women's Health; 3 cohorts (18-22, 45-49, 70-74 years) of 12-14,000 women in each.

Results: Lifetime prevalence of domestic violence (DV) was highest in middle-aged women (12% young, 16% middle-aged, 6% older women;  $p < 0.01$ ). More young women reported recent physical assault than women of other ages (16%, 4%, 1%;  $p < 0.01$ ).

Young women's SF-36 scores were significantly associated with both DV and recent assault. Young women who had experienced a violent relationship (DV group) had lower scores than the non-DV group across all the physical, mental, social and emotional functioning scales of SF-36 (e.g. mental summary scores = 40.5, 46.4,  $t = 16.33$ ,  $p < 0.0001$ ; physical summary scores = 46.4, 49.1,  $t = 10.68$ ,  $p < 0.0001$ ). Women reporting recent assault had worse mental health than those who did not. The differences were clinically and statistically significant ( $p < 0.001$ ).

Conclusion: The more violence young women experienced, the worse was their overall mental health (comprising general mental health, vitality, social and emotional functioning). There was some evidence that mental health of young women who experienced a violent relationship improves if physical aggression ceases. Research now underway aims to provide longitudinal data on the recovery process and what women do to protect themselves from repeated violence.

WICKS D, BRYSON L & MISHRA G. Health and socio-economic class: A survey of a cohort of Australian women *29th Annual Conference of the Public Health Association. Melbourne 5-8 October 1997.*

**Abstract**

This paper examines data from the Australian Longitudinal Study on Women's Health (ALSWH) concerning the relationship between morbidity and socio-economic class for women aged 45-49 years. Morbidity measures are based on recent illness, self reported health status, diagnosis of chronic illness and other measures of physical and mental health status (SF-36). An occupational classification system (ASCO) is used to designate social class since this has proved to be a reliable and accessible indicator of social and economic position (Coxon & Davies, 1986). For purposes of comparison of morbidity, women in the manager and professional (MP) occupational categories were compared with women in the machine operator and manual worker (MM) categories. The study found significant class differences among middle aged women in the experience of morbidity. For example, women in the MM categories were more likely to experience breathing difficulties (22%) than women in the MP categories (15%), chest pain (MM 16%, MP 9%), headaches/migraine (MM 66%, MP 51%) and stiff or painful joints (MM 64%, MP 46%). There are

few gender specific studies of morbidity among Australian women. The data provide a solid foundation for exploring the short and longer term effects of class on the health of a large cohort of Australian women and lay the basis for appropriate policy intervention to mitigate these effects.

## **5.4 PUBLICATIONS**

### **5.4.1 Papers published**

#### **Women's Health Australia**

BROWN WJ, BRYSON L, BYLES JE, DOBSON AJ, MANDERSON L, SCHOFIELD M & WILLIAMS G. (1996). Women's Health Australia: Establishment of The Australian Longitudinal Study on Women's Health. *Journal of Women's Health*; 5: 467-472.

DOBSON A, MISHRA G, BROWN W & REYNOLDS R. Food habits of young and middle-aged women outside the capital cities of Australia. *Australian New Zealand Journal of Public Health*. (To appear).

KENARDY J & BALL K. Disordered eating, weight dissatisfaction and dieting in relation of unwanted childhood sexual experiences in a community sample. *Journal of Psychosomatic Research*. (To appear).

#### **Associated Projects**

Bates L & BROWN WJ. Nurses and doctors, management attitudes and knowledge of domestic violence. *Australian Journal of Advanced Nursing*. (To appear).

BROWN WJ, Alexander J, McDonald B & Mills-Evers T. (1997). Health of Filipinas in the Hunter. *Australian and New Zealand Journal of Public Health*; 21: 214-216.

BROWN WJ & Brown P. (1996). Children, physical activity and better health. *The ACHPER Healthy Lifestyle Journal*; 43: 19-24.

BROWN WJ, LEE C & Nasstasia Y. Heart health for migrant women: A short intervention with Macedonian-Australian women. *Health Promotion Journal of Australia*. (To appear).

BRYSON L. (1996). Poverty: the Gender Dimension. *Australian Options*; 7: 16-19.

BRYSON L & Winter I. (1996). The Poverty of Housing Policy: Newtown 1996 and 1991. *Family Matters*; 45: 41-43.

BRYSON L, Winter I & Lazzarini V. (1996). Global Restructuring and Local Difference in Newtown. *Labour and Industry*; 7: 35-54.

BRYSON L. Economic Restructuring and State Intervention in Holdenist Suburbia: Understanding Urban Poverty in Australia. *International Journal of Urban and Regional Research*. (To appear).

BRYSON L. Economy and welfare; privatisation; political economy. In C Kramarae & D Spender (eds.), *International Encyclopedia of Women's Studies*. London: Harvester Wheatsheaf. (To appear).

BRYSON L. Reshaping Australia's Women's Welfare State. *Australian Journal of Political Science*. (To appear).

BYLES JE. (1997). *Reaching women: Meeting the challenge*. Recruitment Workshop for the National Breast and Cervical Screening Program 14-15 November 1996, Adelaide. Workshop Report, January.

BYLES JE, SCHOFIELD M & Hanrahan P. It would be good to know you're not alone: The needs of women with menstrual symptoms. *Family Practice*. (To appear).

DOBSON A, Porteous J, McElduff P & Alexander H. (1997). Whose diet has changed?. *Australian New Zealand Journal of Public Health*; 21: 147-154.

DOBSON A, Porteous J, McElduff P & Alexander H. (1997). Dietary trends: Estimates from food supply and survey data. *European Journal of Clinical Nutrition*; 51: 193-198.

France K, SCHOFIELD MJ, LEE CL. (1997). Patterns and correlates of hormone replacement therapy use among middle age Australian women. *Women's Health: Research on Gender, Behavior, and Policy*; 3: 21-138.

Harris MA & BYLES JE. A survey of screening compliance among first degree relatives of people with colon cancer in NSW. *Journal of Medical Screening*. (To appear).

Kinlay S, DOBSON AJ, Heller RF & McElduff P. (1996). Risk of primary and recurrent acute myocardial infarction from lipoprotein(a) in men and women. *Journal of the American College of Cardiology*; 28: 870-875.

LEE C. (1997). Review of The Psychology of Women's Health: Progress and challenges in Research and Application. *Journal of Health Psychology*; 2: 116-117.

LEE C. Social context, depression and the transition to motherhood. *British Journal of Health Psychology*. (To appear).

LEE C & BROWN WJ. Changing exercise and diet. In G Byrne & M Sanders (eds.), *Medical Communication Skills: Chapter 9*. Addison Wesley Longman. (To appear).

Lynagh M, SCHOFIELD MJ & Sanson-Fisher R. (1997). School health promotion programs over the past decade: a review of smoking, alcohol and sun protection literature. *Health Promotion International*; 12: 43-60.

McElduff P & DOBSON AJ. (1997). How much and how often: Alcohol and risk of a major coronary event. *British Medical Journal*; 314: 159-1164.

#### **5.4.3 Papers submitted for publication**

BALL K, KENARDY J & LEE C. Relationships between disordered eating and unwanted sexual experiences: A review. *Submitted to Clinical Psychology Review*. April 1997.

BALL K & LEE C. Psychological stress in the etiology of disordered eating. *Submitted to the British Journal of Health Psychology*, February 1997.

BROWN WJ, BRYSON L, BYLES JE, DOBSON AJ, LEE, C, MISHRA G & SCHOFIELD M. Women's Health Australia: Recruitment for a national longitudinal cohort study. *Submitted to Journal of the American Medical Women's Association*. February 1997.

BROWN WJ, DOBSON AJ & MISHRA G. What is a healthy weight range for middle aged women? *Submitted to International Journal of Obesity*. May 1997.

CHIARELLI P & BROWN WJ. Women's waterworks: Prevalence, problems and prevention of urinary incontinence. *Submitted to Women and Health*. June 1997.

MISHRA G & SCHOFIELD MJ. Women's Health Australia: Norms for the Physical and Mental Health Component Summary Scores of the SF-36 for young, middle and older Australian women. *Submitted to Quality of Life Research*. May 1997.

PATTERSON A, BROWN W & Roberts D. Development, prevention and treatment of iron deficiency in women. *Submitted to Nutrition Research*. May 1997.

Roberts DCK, BROWN WJ, BYLES JE & Alexander J. Starving for attention: nutritional risk assessment for older women. *Submitted to Ageing*. February 1997.

SCHOFIELD MJ & MISHRA G. Validity of the SF-12 compared with the SF-36 Health Survey in pilot studies of the Australian Longitudinal Study on Women's Health. *Submitted to the Journal of Health Psychology*. January 1997.

STRAZZARI S, BRYSON L & BROWN WJ. Young women and safe sex: Transitions in contraceptive choice. *Submitted to Women and Health*. June 1997.

YOUNG AF, BYLES JE & DOBSON AJ. Women's satisfaction with general practice consultations. *Ready for submission to The Medical Journal of Australia*. May 1997.

#### **5.5 CONFERENCES ATTENDED**

MISHRA G & YOUNG A

"Introduction to the analysis of hierarchical data", Department of Public Health and Community Medicine, University of Sydney. One-day workshop, Friday 7th February, 1997.

BROWN W

National Physical Activity, Sport and Health conference. Melbourne. 20-21 March 1997.

NSW College of Nursing/NSW Nurses' Association. National Symposium on the nurse practitioner pilot projects. Sydney. 28 February 1997.

## **5.6 ADDITIONAL RESEARCH GRANTS**

DOBSON AJ. (1997). Evaluation of Weight Watchers data. Weight Watchers Australia. Total funding: \$20,000.

DOBSON AJ. (1997). Research Infrastructure Allocation for purchase of Health Related Data Sets. Total funding: \$22,500

DOBSON AJ, BROWN WJ et al. (1997). Consultancy for the Federal Office of Road Safety. Research project on female drivers. Commonwealth Department of Transport and Regional Development. Total funding: \$29,966.

DOBSON AJ, BYLES J & YOUNG M. (1997). The effectiveness of legal protection in the prevention of domestic violence in the lives of young Australian women. Criminology Research Council. Total funding: \$37,050.

SCHOFIELD M & Waite H. (1997). The health of mid-life lesbian women: A pilot study. Australian Research Council. Total funding: \$10,000.

WICKS D. (1997). Young Australian women: Their aspirations regarding work, career, and relationships. Australian Research Council. Total funding: \$10,000.

## **5.7 COMMITTEES**

### **BROWN W**

NSW Health Steering Committee for the Evaluation of the National Women's Health Program.

Commonwealth Department of Health and Family Services. AHMAC Subcommittee on Women's Health - Steering Committee for the Development of Outcomes and Indicators for Women's Health.

National Heart Foundation. National Exercise Advisory Committee.

### **BYLES JE**

Commonwealth Department of Health and Family Services. National Cervical Screening Program - Recruitment Working Party (Chair).

Department of Veterans' Affairs Preventive Care Trial. Central Co-ordinative Committee (Chair).

### **SCHOFIELD M**

Member of the NSW Working Group for Rural and Remote Mental Health Care.

## **5.8 WOMEN'S HEALTH AUSTRALIA STUDENT SEMINAR SERIES**

22 APRIL Kylie Ball - Psychological stress, coping and the etiology of disordered eating

Anne Young - Women's use of health services

6 MAY Amanda Patterson - Iron deficiency in Australian women of childbearing age

Judy Alexander - Evaluation of Weight Watchers data

3 JUNE Stefani Strazzari - Young women and safe sex: Transitions in contraception choice

Gillian Bowes - Young women, menstruation and the media

## **5.9 VISITORS**

The Women's Health Australia researchers have welcomed the following visitors during the first five months of 1997:

Dr Tian Xiangyang, Director, Health Promotion Program Office, Beijing Municipal Institute of Health Education. March 1997

Dr Qiao Lei, Officer, Office of Health VII Project Beijing Municipal Public Health Bureau and Doctor in Charge, World Health Organisation Collaborating Centre for Urban Health. March 1997.

Ms Leonie Middlelink, a post-graduate student with the Department of Human Nutrition from the Wageningen Agricultural University in the Netherlands, has been working with the ALSWH researchers during the current semester. Ms Middlelink's valuable contribution to the 'iron' sub-study is acknowledged by the research team.

## 6. PLANS FOR THE NEXT SIX MONTHS

### 6.1 SUB-STUDIES

During the next six months we will be collecting and/or analysing data from participants in ten sub-studies (see Table 6.1). Care will be taken not to select women in more than one sub-study each year. (For the health services utilisation sub-study we will be trialing a scanning method of data entry, which will mean changes to the formatting used to date in WHA surveys).

**Table 6.1: Sub-studies planned for 1997-98**

Sub-studies 1997	No. of WHA participants			Area	Other participants	Type of study	Stage (June-Dec 97)
	Young	Middle-aged	Older				
Health services utilisation		4,000	4,000	NSW		quantitative	data collection
Eating Disorders	1,000			Australia		quantitative	data collection
Violence (legal protection)	1,000			Australia		quantitative	data collection
Widows			500	Australia and SA		quant/qual	data collection
Contraception	100			Hunter		quant/qual	data collection
Social support			1,000	Australia		quant/qual	data collection
Help seeking for emotional distress		400		NSW		quant/qual	analysis
Menopausal weight change		3,000		Australia		quant/qual	development
Iron deficiency				Hunter	75	intervention study	data collection
Aspirations	100			Australia		quant/qual	development

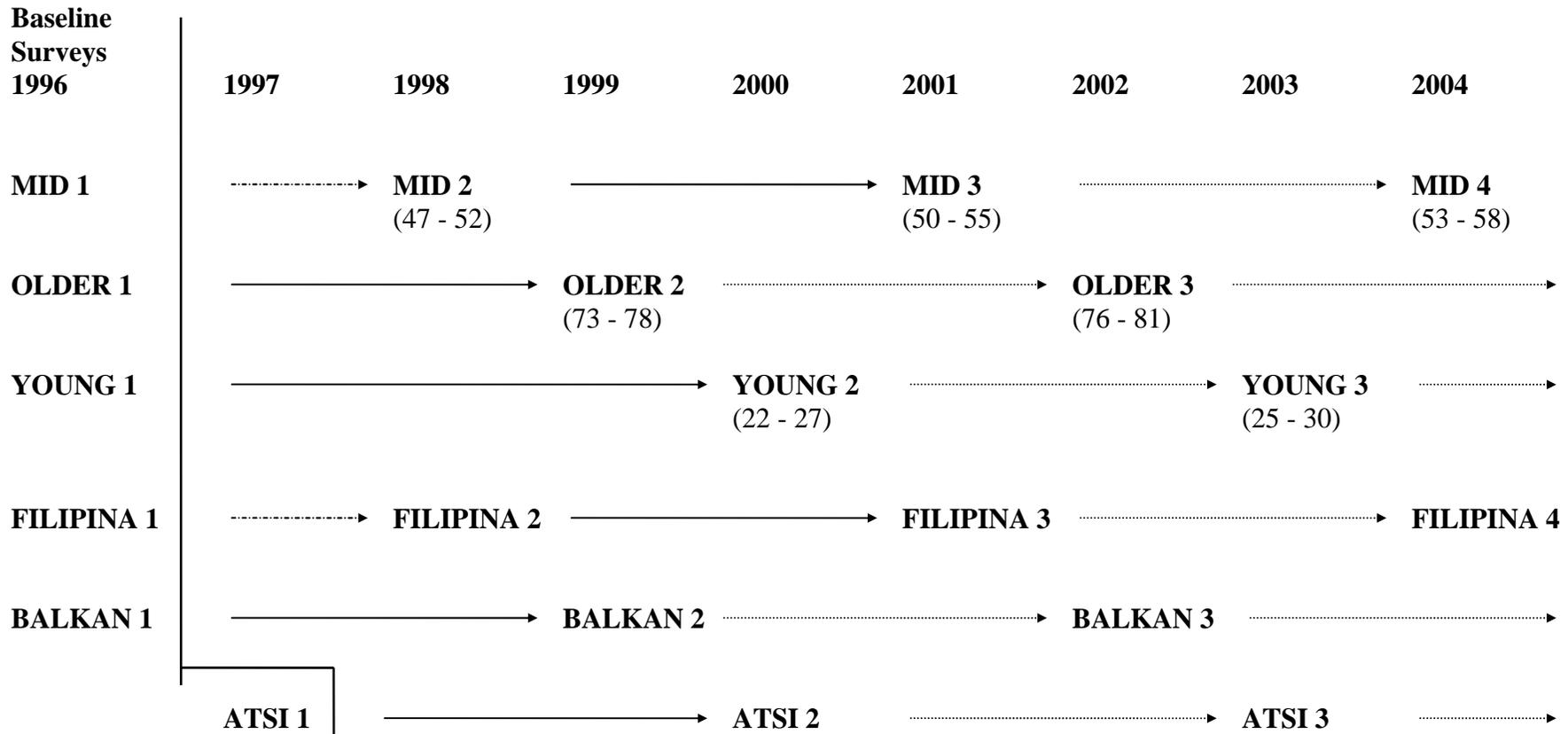
### 6.2 MAIN COHORTS

The first follow-up survey for the middle cohort is planned to take place during the first half of 1998. Development and pilot testing of this survey will therefore occur during the second half of 1997. A plan showing the proposed staged implementation for follow-up of each of the age and special cohorts is shown in Figure 6.2.

### 6.3 MAINTENANCE OF THE THREE COHORTS

During the second half of 1997, we also intend to 'track' those women who were contacted this year in connection with the consent for access to Medicare records, but whose packages were 'returned to sender', or for whom follow-up contact attempts (by telephone) were unsuccessful. In the first instance, we will use the electronic white pages to track women who may have moved house, but who are living in the same region. We will also seek the assistance of the Health Insurance Commission in finding change of addresses for participants.

**Figure 6.2 Proposed follow-up of study participants (1998 - 2004)**



**Key - funding triennium:**

- > 1995-1998
- > 1998-2001
- .....> 2001-2004

## 7. REFERENCES

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Thomson R & Holland J. (1994). Young women and safer (Hetero)Sex: Context, constraints and strategies. In S Wilkinson & C Kitzinger (eds.), *Women and health: Feminist perspective*. London: Taylor & Francis.

Ungerson C. (1994). Morals and politics in 'payment for care': An introductory note. In A Evers, M Pijl & C Ungerson (eds), *Payments for Care*. Aldershot, England: Avebury.

## **PART B**

### **1. NATIONAL ADVISORY COMMITTEE**

#### **1.1 MINUTES OF THE LAST MEETING**

*Minutes of the third meeting of the National Advisory Committee for the  
Australian Longitudinal Study on Women's Health*

Tuesday December 3 1996, 10.15 am - 3.30 pm  
Department of Health & Family Services, Woden ACT

**Present:** Rhonda Galbally (Chair), Dorothy Broom, Gloria Sutherland, Jeanette Ward, Renata Watkinson, Agnes Whiten, Wendy Brown, Julie Byles, Annette Dobson, Margot Schofield, Gita Mishra, Margaret Kelaher, Gail Williams.  
Brendan Gibson, Jill Guthrie, Manoa Renwick, Liz Furler (present for first part of meeting).

**Apologies:** Sally Redman, Lois Bryson, Lenore Manderson.

#### 1. Welcome

Rhonda Galbally welcomed everyone to the meeting and explained that Liz Furler (acting First Assistant Secretary - Public Health Division) would be present only for the initial part of the meeting. It was agreed that agenda item 6 be moved forward.

#### 2. Minutes of the last meeting

The minutes of the previous meeting were accepted - no matters arising. The minutes are in the back of Report 5.

#### 3. Update on activities in the Public Health Division, Department of Health and Family Services

Annette raised concerns about future funding and the implications this may have for follow-up of the baseline cohorts.

Liz Furler explained that the National Public Health Partnership agreement was being developed. Areas of activity include: work force, quality and standards, research and development, and public health information. Liz suggested that we should keep in touch with activities in the area of research and development, and in the development of a national public health information base - the framework for both of these is likely to be completed by June 1997.

Rhonda Galbally suggested that the Women's Health Australia research team might consider holding a forum in March or April to provide results from the

baseline surveys, with implications for public policy and health services. Senior Federal and State public servants would be invited.

*Action:* Manoa Renwick will contact the groups responsible for the research and development work, the public health information work, and the National Social Health Atlas, to see how the WHA research outcomes can link with the development of these strategies. Manoa will then advise the researchers of the best strategy/timing for a high profile forum for the project. Funding to support this could be sought from the Department of Health and Family Services.

Annette pointed out that an alternative strategy for future funding would be through a program grant from the NHMRC. If this was to occur we would need to submit an application early in 1998, for funding in 1999. This would leave a 'gap' in funding for the second half of 1998, and the researchers would be unaware of the outcome until December 1998, which would make forward planning extremely difficult.

It was agreed that the best strategy would be to seek funding under the Department of Health and Family Services Public Health initiatives in the first instance.

#### 4. Progress at the University of Queensland

##### 4.1 *Indigenous cohort*

Gail Williams reported on progress with the indigenous cohort. There has been detailed liaison with indigenous communities in Brisbane, Toowoomba, Cherbourg, Stradbroke Island and Worrabinda. The aim being to balance consultation with communities with the need for scientific rigour. Issues for pilot studies have been negotiated and pilot studies are ready to proceed early in the new year. 'Personal' health questions are not acceptable to the women in these communities.

Gloria Sutherland raised the issue of whether the women saw this component of the study in the context of the larger project. Gail explained that the communities see a need for action rather than information.

Gloria is interested in exploring the issue of indigenous and/or female providers for ATSI health services. She will send information to Gail.

Rhonda Galbally asked about the prospect of getting comparable quantitative data from the indigenous cohorts. Gail explained that different communities might agree to different aspects of the questionnaire (draft in the report) but the potential is there to collect comparable data, as well as some clinical data.

#### 4.2 *Migrant cohorts*

Margaret Kelaher reported on the Filipina cohort. Data collection has been completed with this group and data books are available. Margaret outlined the significant findings which relate to the issue of Filipina brides and Filipina women married to Filipinos.

Margaret then detailed progress with the cohorts from the Former Yugoslav Republics. Data collection from women from Serbia is almost complete and a new PhD student, funded with supplementary funding from the Department of Health and Family Services, is beginning to collect data from Bosnian and Muslim women.

#### 5. Progress at the University of Newcastle

Annette Dobson reported on recruitment for the three main cohorts and outlined the response rates and reasons for non-participation in the study. The response rates are shown in the report. The lower response rate in the older cohort probably reflects the fact that the HIC data base is not up-to-date. In particular, many of the older women may have died without notification to Medicare.

Major reasons for non-participation were "couldn't be bothered" " no time" and general disinterest. Privacy was an issue for a few women. Some of the older women found the survey distressing. Reasons are detailed in the report.

Response rates were highest for middle aged and lowest for oldest group in Northern Territory. Response rates were reasonably consistent in remote areas.

Jeanette Ward asked what the women had consented to at this stage. Annette explained that that most had consented to participate and to be contacted again - either for follow up or for sub-studies. Most recruits were delighted to be in the study. Consent to access Medicare data has not yet been sought, but women were informed that consent will be sought at a later stage.

Gita Mishra then discussed the representativeness of the three age cohorts in comparison with data from the 1991 Census. There are more women who are married or in defacto relationships in the study sample, particularly in the younger cohort. Employed women are under represented in the younger group and over represented in the middle aged group. Study appears to have a greater proportion of tertiary educated women, but this is difficult to confirm because of missing data in the 1991 Census. This may be resolved when the 1996 census data are released. There is slight over representation of Australian born women but good representation of European born women in the older cohort and of Asian born women in the middle group. Representation of Aboriginal women is similar to Census data. The conclusion is that women in the study are fairly representative of women in the general population.

Julie Byles then discussed the issue of requesting consent from women for access to HIC data. Julie described the focus groups and pilot studies which have been carried out in this topic. Young women knew little about Medicare, the middle

aged women were concerned about privacy, and the older women thought access to Medicare was only a problem if they 'had something to hide'. Pilot studies in middle aged women elicited a response from 65% of the women, using one letter and a reminder. Most non-respondents hadn't got around to it. 48% of older women consented without a reminder. Requests for access to Medicare data from the main cohorts will be sent out with newsletters early in the new year. A sub-sample will be followed up more intensively to allow record linkage on a representative group.

Rhonda Galbally asked about differences between women who grant access to HIC data and women who do not. Wendy Brown explained that there is a wealth of demographic data to enable these comparisons to be made (in due course!).

Gail asked about differences between early and late respondents. Wendy explained that the response to the last mail out was very low, so we may not have the numbers to explore this. We could look at who responded to the first and second mail outs and it will be interesting to see whether the later respondents are also the first to drop out. Gloria Sutherland commented that similar results have been seen for opt-off cancer registries

Wendy Brown then reported on the qualitative data. These data are the comments provided by women on the final page of the questionnaire. These data are being entered into a data base and coded by key words. To date only data for the middle cohort have been entered. 9% of respondents wrote comments. Qualitative data will be used to support the quantitative data.

Wendy then outlined issues relating to the questionnaire itself and described the areas where women would like to be asked more questions. These will be considered for future surveys, and will help to identify areas for sub-studies. Details are in the report.

## 6. The Launch

There was some discussion about the launch which was to be held in Parliament House later in the afternoon. Wendy raised concerns that the information contained in the data books should be used judiciously and placed in an appropriate context. It was decided that data books would not be distributed to the press but that the press would be encouraged to interview members of the research team and talk to members of the National Advisory Committee if appropriate, and that these people could refer to the data books if the press wanted data about a specific health issue.

The major issues raised during the launch include:

- ◇ Increased costs of GP visits in rural and remote areas
- ◇ Younger women 27% under weight but proportion of overweight middle aged women increasing. Focus needs to be on interventions, with care taken on this issue because of psychiatric co-morbidity of overweight (Rhonda).
- ◇ Younger women have greater expectations of their doctors (greater degree of consumerism).
- ◇ A high proportion of middle aged women report menstrual and menopausal problems. Also, 20% of women are currently on HRT and 1/3 have ever been on HRT
- ◇ Need for culturally sensitive health workers for NESB women, who are objective and separate from the community.

Gail Williams pointed out the need to depict the indigenous component of the study as a priority area, and to emphasise the importance of consultation.

Rhonda Galbally suggested that the focus for the special cohorts be on the process of establishing the cohorts.

#### 7. Long term plans for the study

Rhonda suggested that it might be a good idea for the research team to offer to have a briefing whereby the study results would be disseminated to members of Parliament so that the implications for future health policy and practice could be highlighted.

Rhonda reiterated the need for a forum about the project. Julie suggested a need to include broader women's health groups, and Rhonda suggested that senior public servants be invited.

Rhonda suggested that we need to stress how the data can be useful to the public health partnership. The forum should be by invitation only. Jeanette stressed the importance of including the AHMAC sub-committee on women's health.

Rhonda asked whether this could be a broader information sharing forum for research. As the University of Newcastle is organising a women's health promotion conference for next year this might not be appropriate.

Manoa will liaise within the Department to ensure the timing is right. Annette stressed the need to have the project included in the partnership, preferably as a federally funded alternative. If this falls through we should use NHMRC as a back up.

Brendan suggested that the meeting be held in March to coincide with the national partnership meeting. There is a need to position the project in a "public

health" research development context. Annette stressed the importance of mapping the health information potential of the project.

Rhonda suggested that the government should be encouraged to 'own' the study.

Annette Dobson proposed that in future the cohorts should not all be surveyed in the same year (this has been somewhat exhausting!). It was proposed that the mid cohort be resurveyed in 1998, with the young and older cohorts following in 1999 and 2000. Because of the danger of losing member of the older cohort, there was general agreement that this cohort should be the first to be 'revisited'. Filipina women will be surveyed in 1998. Women from the Former Yugoslav Republic in 1999 and the ATSI women in the year 2000. This will allow time for study results to be published and for comparisons between groups to be made.

There being no other business the meeting closed at 2.30 so that members could travel to Parliament House to attend the launch of the baseline data.

The date for the next meeting will be advised.

## **1.2 PLANS FOR THE NEXT MEETING**

It is proposed the next meeting of the National Advisory Committee will be held in Canberra in conjunction with a Parliamentary Briefing on the project. Since the last meeting of the National Advisory Committee, when this issue was raised, the researchers have been informed by Senator Newman's advisers that the most appropriate time for a briefing would be during the Spring Session of parliament. It is likely therefore that the next meeting of the National Advisory Committee will be held in August or September.

## **2. COMMUNICATIONS STRATEGY**

The major communication strategies planned for 1997 were (a) to send a summary of the baseline results to all participants, and (b) to prepare the baseline findings for presentations at conferences and for submission for publication.

In March this year all women who completed the baseline survey and consented to participate in the longitudinal study were sent a newsletter which provided feedback on the findings of the baseline survey (see Appendix 5). Response to the newsletter has been very favourable, with many calls from women saying how much they appreciate the feedback.

Since completion of the baseline surveys last September, three papers with initial results have been accepted for publication, and eleven (check) more have been submitted for editorial review (to end of May 1997). Seventeen abstracts have been submitted for presentation at conferences, which will be held throughout Australia and in Beijing, in the second half of 1997 (see section 5.3.3 for details).

Following the successful 'launch' of the baseline data books by the Minister for Health, Dr Wooldridge, in Canberra last December, the researches have continued to attract media coverage for the project, with print articles appearing in 20 publications, radio interviews being broadcast on 16 stations throughout Australia and 6 television interviews on local and national television (see Appendix 6). During the first half of this year, an audio tape has also been produced, featuring interviews with the researchers about the main findings of the baseline surveys. This tape will be made available to radio stations throughout Australia. The contribution of our media and communications student, Ms Eleanor Gorman, to the development and production of this tape, is acknowledged by the research team.

## **APPENDICES**

**1. CONFIDENTIALITY AGREEMENT**

Not available online.

**2. KEY WORDS AND THEMES FOR QUALITATIVE RESEARCH -  
MIDDLE AND OLDER AGE GROUPS**

Not available on line.

**3. MATERIALS USED FOR MEDICARE CONSENT**

Not available on line.

**4. MEMORANDUM OF UNDERSTANDING FOR COLLABORATORS**

Not available on line.

**5. NEWSLETTER - MARCH 1997**

For a copy of the 1997 ALSWH participant newsletter please visit:

<http://www.newcastle.edu.au/centre/wha/Reports/newsletters.html>

**6. MEDIA COVERAGE**

Not available on line.