
Men's health practices within dual income families

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APPENDICES

- Appendix 1: Household survey - questionnaire, health practices in dual income families
- Appendix 2: The envelope containing the household survey as was addressed to the occupant
- Appendix 3: Men's information sheet, focus group and individual interviews
- Appendix 4: Focus groups and individual interview, consent form
- Appendix 5: Information on research complaints procedure for interviewees
- Appendix 6: Semi structured interview questions, used as a guide for individual interviews
- Appendix 7: Ethics Approval
- Appendix 8: Journal article : Fathers struggling for relevance in the care of their terminally ill child

**APPENDIX 1: Household survey - questionnaire, health practices
in dual income families**

Section One**Men and women's role in society**

Below are some common opinions about men and women in society. I would like to know how much you agree/ disagree with these comments. For each statement circle one answer. Keep in mind that there are no right or wrong answers to these statements. I am only interested in your opinion.

Section 1.1 Men and work

- Q1. Being in full-time work is more important to a man than a woman.
- Strongly agree
 - Agree
 - Disagree
 - Strongly disagree
- Q2. Men should be major breadwinners in a family.
- Strongly agree
 - Agree
 - Disagree
 - Strongly disagree
- Q3. A man should be given a job in preference to a woman, if he has a family to support and she does not.
- Strongly agree
 - Agree
 - Disagree
 - Strongly disagree
- Q4. The possibility of pregnancy should not make women less suitable to employers than a man.
- Strongly agree
 - Agree
 - Disagree
 - Strongly disagree
- Q5. Young boys should not be deterred from choosing a nursing career.
- Strongly agree
 - Agree
 - Disagree
 - Strongly disagree

- Q6. Women are just as suited to dealing with technical problems as men.
- Strongly agree
 - Agree
 - Disagree
 - Strongly disagree
- Q7. Women should have opportunities equal to that of men when it comes to gaining employment.
- Strongly agree
 - Agree
 - Disagree
 - Strongly disagree
- Q8. Most men would prefer to raise their children than go to work or pursue a career.
- Strongly agree
 - Agree
 - Disagree
 - Strongly disagree
- Q9. It is more important for a man to have a prestigious job than it is for a woman.
- Strongly agree
 - Agree
 - Disagree
 - Strongly disagree

Section 1.2 Women and the family

- Q10. It is only natural for women to know how to care for young children
- Strongly agree
 - Agree
 - Disagree
 - Strongly disagree
- Q11. Women are better than men at caring for sick children
- Strongly agree
 - Agree
 - Disagree
 - Strongly disagree

- Q12. In a single family it is more important for a child to be with the mother than the father
- Strongly agree
 - Agree
 - Disagree
 - Strongly disagree
- Q13. When it comes to decorating the house I let my spouse / partner make the important decisions
- Strongly agree
 - Agree
 - Disagree
 - Strongly disagree

Section 1.3 Fathering today

- Q14. Apart from breast feeding men can be as capable of caring for babies as women are
- Strongly agree
 - Agree
 - Disagree
 - Strongly disagree
- Q15. Children want to have both parents caring for them and caring about them
- Strongly agree
 - Agree
 - Disagree
 - Strongly disagree
- Q16. Society does not give men enough time to be with their children
- Strongly agree
 - Agree
 - Disagree
 - Strongly disagree
- Q17. Most men would like to have the same level of parenting skills that women have
- Strongly agree
 - Agree
 - Disagree
 - Strongly disagree
- Q18. Men want to be more involved with their children than their forefathers were

Section 1.4 Parenting in dual income families

- Q19. Women prefer some form of employment to doing home duties on a full-time basis.
- Strongly agree
 - Agree
 - Disagree
 - Strongly disagree
- Q20. Women can successfully combine a career with motherhood.
- Strongly agree
 - Agree
 - Disagree
 - Strongly disagree
- Q21. Mothers should stay at home when the children are young.
- Strongly agree
 - Agree
 - Disagree
 - Strongly disagree
- Q22. Women who have part-time jobs are able to mix home duties satisfactorily with child care and work commitments.
- Strongly agree
 - Agree
 - Disagree
 - Strongly disagree
- Q23. Many mothers have to go to work because a man's wage is simply not enough to support a family these days.

Section 1.5 Parenting in dual income families

- Q24. When both parents work full-time they *should* have an equal share in parenting and caring for the children.
- Strongly agree
 - Agree
 - Disagree
 - Strongly disagree
- Q25. Finding suitable childcare, when both parents work, is the responsibility of the mother.

- Q26. In principle working parents should share the load of getting children to childcare, before and after work.
- Strongly agree
 - Agree
 - Disagree
 - Strongly disagree
- Q27. If both parents work and the child becomes ill it should be the mother who stays at home to care for the child.
- Strongly agree
 - Agree
 - Disagree
 - Strongly disagree
- Q28. If both parents work full-time the housework should be shared equally between them.
- Strongly agree
 - Agree
 - Disagree
 - Strongly disagree
- Q29. Men should know how to change a nappy.
- Strongly agree
 - Agree
 - Disagree
 - Strongly disagree

Section 1.6 Equality of the sexes

- Q30. Men should be shown how to nurse a sick family member.
- Strongly agree
 - Agree
 - Disagree
 - Strongly disagree
- Q31. Women should be able to check the oil level in their car.
- Strongly agree
 - Agree
 - Disagree
 - Strongly disagree

- Q32. Young Australian men and women do have equal rights.
- Strongly agree
 - Agree
 - Disagree
 - Strongly disagree
- Q33. Equal opportunity for women in the workplace has put too much pressure on the Australian family.
- Strongly agree
 - Agree
 - Disagree
 - Strongly disagree
- Q34. Women have gained equality and it is now time to give men's problems some consideration.
- Strongly agree
 - Agree
 - Disagree
 - Strongly disagree
- Q35. A husband should consider his wife's needs before his own.
- Strongly agree
 - Agree
 - Disagree
 - Strongly disagree
- Q36. Men should be as responsible as women when it comes to planning contraception and having safe sex.

Section 1.7 Sexuality

- Q37. I dislike men who are sexist toward women
- Strongly agree
 - Agree
 - Disagree
 - Strongly disagree
- Q38. I dislike homosexual and lesbian behaviour
- Strongly agree
 - Agree
 - Disagree
 - Strongly disagree

Q39. Homosexuals should have rights equal to those of other members of society

- Strongly agree
- Agree
- Disagree
- Strongly disagree

Q40. Homosexuals and lesbians should be allowed to join the armed forces

- Strongly agree
- Agree
- Disagree
- Strongly disagree

Q41. Homosexuals and lesbians should be allowed to parent a child

- Strongly agree
- Agree
- Disagree
- Strongly disagree

Section Two

Parents who work

Section 2.1 Family structures

Q1. In what type of household do you currently live? (choose one)

- Single and living by yourself
- Single and living with other adults
- Single and living with children
- Living with a spouse / partner and no children
- Living with a spouse / partner with children
- Other, please specify

Q2. Were you a parent in a family at any time during the past 10 years?

- No  Skip to last page
- Yes

Q3. Which of these categories best describes your household over the past 10 years?

- Single and living by yourself
- Single and living with other adults
- Single and living with children
- Living with a spouse / partner and no children
- Living with a spouse / partner with children
- Other, please specify

Q4. Which combination best describes your working arrangement over the 10 years?

- both worked full-time
- I worked full-time and my spouse / partner worked part-time
- I worked full-time and my spouse / partner **did no work** outside the home
- both worked part-time
- I worked part-time and my spouse / partner worked full-time
- I **did no work** outside the home and my spouse / partner worked full-time

Q5. Which group best describes the age of the child / children at the time you both worked?

- less than 2 years
- 2-5 years
- 6 to 12 years
- 12-18 years

Q6. Did any of your children go to child care / day care when you both worked?

- No  Skip to section 2.3
- Yes

Q.7 Over what length of time did your child attend child care / day care?

- less than 6 months
- 6 months – 1 year
- 1-2 years
- 3-4 years
- more than 4 years

Section 2.2 Childcare arrangements**Who usually performed / performs these tasks in your family****Q1.** Getting a child ready for childcare

- Self
- Partner
- Shared
- Grandparent / other

Q2. Driving the child to and from childcare

- Self
- Partner
- Shared
- Grandparent / other

Q3. Giving information about your child's health to staff

- Self
- Partner
- Shared
- Grandparent / other

Q4. Cancelling child care when child was ill

- Self
- Partner
- Shared
- Grandparent / other

Q5. Attending special child care events

- Self
- Partner
- Shared
- Grandparent / other

Q6. Rearranging child care dates / times

- Self
- Partner
- Shared
- Grandparent / other

Q7. Paying the child care fees

- Self
- Partner
- Shared
- Grandparent / other

Q8. Taking a phone call from staff when there was a problem

- Self
- Partner
- Shared
- Grandparent / other

Section 2.3 Episodes of illness

What happened / happens in your family when a child became ill?
(please your answer)


Q1. Who usually looks after a sick child?

- Self
- Spouse / partner
- Grandparent
- Older brother or sister
- Family friend
- Other

Q2. Are you satisfied with this arrangement?

- Yes
- No please explain

Q3. When did you last care for a sick child that had to stay at home?

- Never  Skip to section 2.5
- Between 1 and 4 weeks ago
- Between 1 and 6 months ago
- Between 6 and 12 months ago
- Longer

Q4. For how long did you care for the child?

- Less than a day
- 1 – 2 days
- 3 – 7 days
- 1 – 4 weeks
- More than a month

Q5. How did you find the time to care for the child?

- I took special leave / sick leave from work
- I took holidays / long service leave
- I rearranged my working hours
- I was between jobs / don't work

Q6. If you took leave or rearranged your work times, what was your employer's reaction?

- Very supportive
- Somewhat supportive
- Neutral
- Not supportive

Section 2.4 Typical activities performed for sick children

How often did you / do you - do these tasks when your child is ill?

Q1. Treating fever

- Always
- Often
- Sometimes
- Not attempted
- Not applicable

Q2. Comforting a child in pain

- Always
- Often
- Sometimes
- Not attempted
- Not applicable

Q3. Cleaning up vomit

- Always
- Often
- Sometimes
- Not attempted
- Not applicable

Q4. Toileting a child with diarrhoea

- Always
- Often
- Sometimes
- Not attempted
- Not applicable

Q5. Give medication

- Always
- Often
- Sometimes
- Not attempted
- Not applicable

Q6. Comforting a child during a medical procedure

- Always
- Often
- Sometimes
- Not attempted
- Not applicable

Q7. Explaining an illness / health problem to a child

- Always
- Often
- Sometimes
- Not attempted
- Not applicable

Q8. Bandaging of a sprain

- Always
- Often
- Sometimes
- Not attempted
- Not applicable

Q9. Treatment of a burn or scold

- Always
- Often
- Sometimes
- Not attempted
- Not applicable

Q10. Treating a sting of bite

- Always
- Often
- Sometimes
- Not attempted
- Not applicable

Section 2.5 Health promotion

Here are some examples of health promotion activities performed by parents. How often were you / are you directly involved in performing these tasks (please circle your answer).

Response options: almost always* - often* - sometimes* - not attempted* - not applicable*.

Q1. Applying anti sun bun lotion

- Almost always
- Often
- Sometimes
- Not attempted
- Not applicable

Q2. Making sure seat belts or restraints are worn

- Almost always
- Often
- Sometimes
- Not attempted
- Not applicable

Q3. Keeping medicines and poisons locked away

- Almost always
- Often
- Sometimes
- Not attempted
- Not applicable

Q4. Surveillance of children near fire / stoves

- Almost always
- Often
- Sometimes
- Not attempted
- Not applicable

Section 2.6 Sharing home duties

Only answer this section if your spouse / partner returned to work after having had a child. You can answer this section by yourself or in collaboration with your spouse / partner

I answered this section ..

- By myself
- With my wife / partner

Indicate the amount of time you spent on the duties listed below when your wife / partner became a working mother (please circle)

Q1. Grocery shopping

- I did less
- I did the same
- I did a little more
- I did a lot more

Q2. Cooking

- I did less
- I did the same
- I did a little more
- I did a lot more

Q3. Washing the dishes

- I did less
- I did the same
- I did a little more
- I did a lot more

Q4. Tidying up the house

- I did less
- I did the same
- I did a little more
- I did a lot more

Q5. Vacuuming and dusting

- I did less
- I did the same
- I did a little more
- I did a lot more

Q6. Making beds

- I did less
- I did the same
- I did a little more
- I did a lot more

Q7. Washing the cloths

- I did less
- I did the same
- I did a little more
- I did a lot more

Q8. Ironing

- I did less
- I did the same
- I did a little more
- I did a lot more

Q9. Pet care

- I did less
- I did the same
- I did a little more
- I did a lot more

Q10. Gardening

- I did less
- I did the same
- I did a little more
- I did a lot more

Q11. Car maintenance

- I did less
- I did the same
- I did a little more
- I did a lot more

Q12. Home maintenance

- I did less
- I did the same
- I did a little more
- I did a lot more

Q13. Tidying up the shed / garage

- I did less
- I did the same
- I did a little more
- I did a lot more

Section Three**Knowledge of health and health practice****Section 3.1 Knowledge of health and health practice**

This section is about health topics you may have been taught at school or elsewhere.

Were you taught about ...

Q1. First aid

- Yes
- No
- Uncertain

Q2. Cardiac resuscitation

- Yes
- No
- Uncertain

Q3. General nursing care

- Yes
- No
- Uncertain

Q4. Care of an infant

- Yes
- No
- Uncertain

Q5. About a balanced diet and food groups

- Yes
- No
- Uncertain

Q6. Occupational health and safety

- Yes
- No
- Uncertain

Q7. Family planning

- Yes
- No
- Uncertain

Q8. Safe sex

- Yes
- No
- Uncertain

Q9. Common childhood illnesses

- Yes
- No
- Uncertain

Q10. Types of immunisation

- Yes
- No
- Uncertain

Q11. Administration of medications

- Yes
- No
- Uncertain

Q12. Personal hygiene

- Yes
- No
- Uncertain

Section 3.2 Looking after a new born child

For each of the activities listed below please indicate the degree of difficulty you experienced in relation to managing babies / infants.

Q1. Bathing a child

- Not attempted
- Difficult but managed
- Not difficult

Q2. Changing a nappy preparing bottle feeds

- Not attempted
- Difficult but managed
- Not difficult

Q3. Getting up in the night to a crying baby

- Not attempted
- Difficult but managed
- Not difficult

Q4. Cleaning nappies

- Not attempted
- Difficult but managed
- Not difficult

Q5. Putting baby to sleep

- Not attempted
- Difficult but managed
- Not difficult

Q6. Giving medication

- Not attempted
- Difficult but managed
- Not difficult

Q7. Calming a screaming infant

- Not attempted
- Difficult but managed
- Not difficult

Section 3.3 Family health problems

Please cross the health problems in your family at present and then indicate who is affected.

Q1. A short term illness (e.g. cold or flue)

- Spouse / partner
- Son
- Daughter
- Other relative

Q2. A recent injury (e.g. burn, laceration, broken bone, sprain)

- Spouse / partner
- Son
- Daughter
- Other relative

Q3. A chronic physical health problem (e.g. asthma, diabetes, epilepsy, chronic fatigue syndrome)

- Spouse / partner
- Son
- Daughter
- Other relative

Q4. A physical disability (e.g. hearing / physical impairment, immobility)

- Spouse / partner
- Son
- Daughter
- Other relative

Q5. A medical investigation (e.g. blood sample, urine test, x – ray, CAT scan)

- Spouse / partner
- Son
- Daughter
- Other relative

Q6. A childhood illness (e.g. measles, chicken pox, mumps)


- Spouse / partner
- Son
- Daughter
- Other relative

Q7. A mental health problem (e.g. eating disorder, depression, post natal depression, schizophrenia, attention deficit disorder)

- Spouse / partner
- Son
- Daughter
- Other relative

Section 3.4 Medication use and purchase

Q1. How often have you visited a pharmacy in the past year

- Never  Skip to question 6
- 1-5 times
- 6-10 times
- 11-20 times

Q2. Have you purchased drugs in a pharmacy in the past year


- No  Skip to question 6
- Yes


Q3. What type of medications did you buy?

- Non – prescription drugs (e.g. Panadol)
- Medications that require a doctors prescription
- Both

- Q4. How often did staff tell you how to give the correct dose of prescription drugs?**
- Never
 - Rarely
 - Sometime
 - Often
 - Always
- Q5. How often did staff tell you about the side effects of prescription drugs?**
- Never
 - Rarely
 - Sometimes
 - Often
 - Always
- Q6. Do you ever suggest to a family member that they take medications (e.g. or pain relief)?**
- No
 - Rarely
 - Sometimes
- Q7. In general terms, do you consider that men and women have differing knowledge about medications used in the family.**
- Men know more
 - Men know about the same
 - Men know less
 - Men know much less

Section 3.5 Children and medication

- Q8. Have any of the children in your family ever taken regular medication?**
- No  Skip to question 10
 - Yes
- Q9. Who gave the medication?**
- The child
 - My spouse / partner
 - Myself
 - Other

- Q10. Who usually gives medicines to the children in your family?**
- My spouse / partner
 - Myself
 - Relative
 - Other
- Q11. Have you ever given pain killers or medicines for colds to your children?**
- No  Skip to question 13
 - Yes
- Q12. How confident do you feel about calculating the dose required?**
- Not at all confident
 - Reasonably confident
 - Very confident
- Q13. How comfortable would you feel about telephoning a pharmacy to ask for advice about the medication you or a family member was taking?**
- Not at all confident
 - Reasonably confident
 - Very confident

Section Four

Your personal details

Please answer these questions accurately so that we can examine the links between, family structure, lifestyle and health practices within the family.

- Q1. your sex**
- male
 - female
- Q2. age last birthday** years
- Q3. your birth place**
- Australia
 - Overseas
- Q4. mother's birth place**
- Australia
 - Overseas
- Q5. father's birth place**
- Australia
 - Overseas

- Q6. Do you speak a language other than English at home?**
- No, English only
- Yes, Italian
- Yes, Greek
- Yes, Cantonese
- Yes, Mandarin
- Yes, Arabic
- Yes, Vietnamese
- Yes, other, specify
.....
- Q7. What is your Ancestry?**
- British
- Irish
- Italian
- German
- Greek
- Chinese
- Australian
- Aboriginal or Torres Strait Islander
- Other, specify
.....
- Q8. In the main job held last week, what was your occupation? (e.g. cook, farmer)**
- Q9. In the main job you held were you a:**
- Wage earner?
- Business owner with employees?
- Business owner without employees?
- A helper not receiving wages?
- Q10. What is your highest level of schooling?**
- Never attended school
- Primary school
- Some high school (yr. 8-11)
- Completed high school (yr. 12)
- Technical or trade certificate
- Tertiary / University courses
- Tertiary / University qualification

Q11. What is your religion?

- Roman catholic
- Anglican (Church of England)
- Uniting Church
- Presbyterian
- Greek Orthodox
- Baptist
- Lutheran
- Islam
- Buddhism
- Other, specify

.....

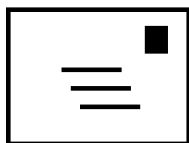
Q12. What is your gross income per year?

- \$10,000 – or less
- \$10,001 - \$20,000
- \$20,001 - \$35,000
- \$35,001 - \$50,000
- \$50,001 - \$100,000
- \$100,000 or more

Q13. What is your partner's / spouse's gross income per year?

- \$10,000 – or less
- \$10,001 - \$20,000
- \$20,001 - \$35,000
- \$35,001 - \$50,000
- \$50,001 - \$100,000
- \$100,000 or more

**APPENDIX 2: The envelope containing the household survey
as was addressed to the occupant**



To the Parent or potential parent

Men contributing to family health

A 15 minute survey that will make a difference to fathers of the future

APPENDIX 3: Men's information sheet, focus group and individual interviews



Research into Men's Contribution to Health Care and
Health Promotion on Dual Income Families

Letter / information sheet to participants

Dear Sir

The purpose of this letter is to explain my research project and ask for your participation in it. As you are undoubtedly aware the role of men and women in our society has changed substantially over the last twenty years. Restructuring of the labour force has resulted in job changes and an increase in the number of working mothers. Consequently men's lives are quite different from that of their forefathers.

As part of my studies towards a Doctor of Philosophy in Public Health at the University of Adelaide, I am undertaking several group discussions/interviews that are designed to explore the ways in which men contribute to health care and health promotion in dual income families. I will also be testing the quality of a questionnaire that I intend to use to survey 1,000 men on this subject.

The aim of the study is to identify what men currently do in relation to providing health care and to use this information to create appropriate services and resources in support of men in this role.

I am asking you to participate in a group discussion with other men on this subject. You have similar qualities to the men I would include in the group discussion. There are no right or wrong answers to the questions I will ask, as I am only interested in men's opinions and what they do. The discussion/interviews would take no more than 60 minutes of your time. I understand that your participation will be purely voluntary and you may withdraw from the discussion at any time.

So that I don't miss anything you tell me I will need to tape record each discussion. All the information you provide is confidential and the material recorded will be kept in a locked cabinet in my office. Whilst this research will most likely produce valuable information and be widely publicised your name will not be mentioned. Should you participate I would be very pleased to forward a copy of the findings of this research to you on request.

Thank you in anticipation of your support

Sincerely

TA Laws Grad Dip Pub Health, Grad Dip Ed., Bach Eco,
LECTURER
DIVISION OF HEALTH SCIENCES
UNIVERSITY OF SOUTH AUSTRALIA

APPENDIX 4 Focus groups and individual interview, consent form

**Research into Men's Contribution to Health Care and Health Promotion on
Dual Income Families**

Interviewee Consent Form


This research is carried out by Tom Laws a Doctor of Philosophy student at the University of Adelaide who has undertaken to keep totally confidential all the information given by you. To fully ensure that an accidental breach of confidentiality does not occur, your name will not appear on any of the information provided by you. Instead the data recorded from this information you give will be allocated a code number known only to myself and my research supervisor. This is important research that will very likely produce useful information the results will be widely publicised. However, your name will not be mention in conjunction with the result of this research or in another way.

As explained in the introductory letter that accompanies this form, the main aim of this research is to identify the ways in which men contribute to health care and health promotion in families. It is expected that this knowledge will be used to guide the creation of appropriate services and resources in support of men in this role.

Your participation in this research is highly valued and voluntary. If there are questions you have about the research please ask me for an explanation at any time. If you become upset or uncomfortable and do not wish to continue with a discussion/interview, please let me know and we will stop immediately and take a break. You may withdraw from the research without explanation at any time.

The interview will be taped using a micro recorder and later written out for the purpose of analysis. At the completion of the interview the tape will be stoped and stored by me in a locked cabinet. All written records and recordings will remain totally confidential

If you have no questions to ask of me in relation to this research and are willing to participate please sign the consent section below

----------

I have read and understood the *Introductory Letter* that provides information on the study as well as the above information, and on this basis I volunteer to be part of a group discussion/interview.

Name of Interviewee ID No. (allocated by T. Laws)

Interviewee's Signature Date.....

Signature of Interviewer Date.....

APPENDIX 5 Information on research complaints procedure for interviewees



THE UNIVERSITY OF ADELAIDE
 HUMAN RESEARCH ETHICS COMMITTEE

Document for people who are subjects in a research project

CONTACTS FOR INFORMATION ON PROJECT AND INDEPENDENT
 COMPLAINTS PROCEDURE

The Human Research Ethics Committee is obliged to monitor approved research projects. In conjunction with other forms of monitoring it is necessary to provide an independent and confidential reporting mechanism to assure quality assurance of the institutional ethics committee system. This is done by providing research subjects with an additional avenue for raising concerns regarding the conduct of any research in which they are involved.

The following study has been reviewed and approved by the University of Adelaide Human Research Ethics Committee:

Project title: **Health Practices of Men within dual Income Families in South Australia**

.....

1. If you have questions or problems associated with the practical aspects of your participation in the project, or wish to raise a concern or complaint about the project, then you should consult the project co-ordinator:

Name: ...Prof. Tony Worsley.....

telephone: 83033576.....

2. If you wish to discuss with an independent person matters related to
 - making a complaint, or
 - raising concerns on the conduct of the project, or
 - the University policy on research involving human subjects, or
 - your rights as a participant

**APPENDIX 6: Semi structured interview questions,
used as a guide for individual interviews**

Semi structured interview question.

The topics and allied questions were derived from the literature review chapters and were designed to identify the actual health practices of the men at interview and to gain some idea of the frequency of these practices (normal practice, occasional practice, infrequent practice, never attempted). The opening question on role models was designed to gain background information on men's notion of women work and women's work as they had understood it in their upbringing. This notion was later extended to their views on working mothers and provided valuable insight in the thematic analysis.

- Topic: Division of labour – Parents as role models
Question: *How would you characterise your mother's and father's work when you were a child?*
- Topic: Division of labour – Child care
Question: *How do you and your wife / partner manage childcare?*
- Topic: Division of labour – Health practices: Medical appointments
Question: *If the children were sick, who was most likely to take them to the doctors?*
- Topic: Division of labour – Health practices: medications
Question: *Who normally gives medications to the children?*
- Topic: Division of labour – Health practices: caring for a sick child
Question: *Who normally cares for the sick child in your family?*
- Topic: Division of labour – Health practices: nocturnal responsibilities
Question: *Who normally gets up in the night for the children?*
- Topic: Health promotion – Sexual / reproductive health
Question: *When it comes to sex, what sort of things do you tell them?*
- Topic: Transmission of health knowledge
Question: *Can you think of information or skills your father may have passed onto you about health matters?*
- Topic: Health promotion – Health prompting activities
Question: *Are there any health prompting activities that you focus on?*
- Topic: Health promotion – Mental health
Question: *Are there things you do to promote wellbeing within your family?*
- Topic: Accidents and injuries
Question: *Is there anything you do to prevent accidents?*
- Topic: Occupational Health & Safety
Question: *How does occupational health and safety relate to your children?*
- Topic: Disability
Question: *Do any of your children have a disability?*
- Topic: Health literacy
Question: *Where do you men get your health information from?*
- Topic: Skills acquisition
Question: *Where did you men learn your health practices?*

APPENDIX 7: Ethics approval



OFFICE OF THE VICE-CHANCELLOR

2 November 00

Professor A F Worsley
PUBLIC HEALTH

Dear Professor Worsley

H/54/00 *HEALTH PRACTICES OF MEN WITHIN DUAL INCOME FAMILIES IN SOUTH AUSTRALIA*

I write to advise you that the Human Research Ethics Committee has approved the above project on the basis that you will also provide interviewees with the Committee's contacts/complaints document.

A copy of the endorsed application form is enclosed for your records.


Approval is current for one year. The expiry date for this project is: **30 November 2001**

Where possible, subjects taking part in the study should be given a copy of the Information Sheet and the signed Consent Form to retain.

Please note that any change to the project which may affect its ethical aspects will invalidate the project's approval. In such cases an amended protocol must be submitted to the Committee for further approval.

A renewal/status report form is enclosed for future use. Please fill this in prior to the above expiry date and send to the Committee's Secretary. Applications for renewal must include a brief report on the project's progress and any ethical issues which may have arisen. Similarly, the Committee should be informed if the project has been completed, has lapsed, or been withdrawn.

Yours sincerely,

CE MORTENSEN
Convenor
Human Research Ethics Committee

Enquiries: Helen Malby, Secretary, Human Research Ethics Committee

Postal Address: ADELAIDE UNIVERSITY, SA 5005, AUSTRALIA
Tel: (08) 830-34014 Fax: (08) 830-33417 Email: helen.malby@adelaide.edu.au



OFFICE OF THE VICE-CHANCELLOR

Applicant: PROFESSOR A F WORSLEY
Department: PUBLIC HEALTH
Project Title: HEALTH PRACTICES OF MEN WITHIN DUAL INCOME FAMILIES IN SOUTH AUSTRALIA

THE UNIVERSITY OF ADELAIDE HUMAN RESEARCH ETHICS COMMITTEE

Project No H/54/00

APPROVED for the period until 30 November 2001

noting that this study involves PhD candidate Mr Thomas A Laws

Refer also to the accompanying letter setting out requirements applying to approval.

Professor CE Mortensen
Convenor

Date - 2 NOV 2000

Enquiries: Helen Malby, Secretary, Human Research Ethics Committee

Postal Address: ADELAIDE UNIVERSITY, SA 5005, AUSTRALIA
Tel: (08) 830-34014 Fax: (08) 830-33417 Email: helen.malby@adelaide.edu.au

PROJECT NO: H/54/00

THE UNIVERSITY OF ADELAIDE HUMAN RESEARCH ETHICS COMMITTEE

Applications will be considered in terms of the University's guidelines on the ethics of human research, based on the requirements of the National Statement on Ethical Conduct in Research Involving Humans, 1999 - refer application information material, including the list of headings applying to all applications. Submit the completed application including Information Sheet and Consent Form with 9 duplicate copies, to the Secretary, Human Research Ethics Committee, Office of the Vice-Chancellor, University of Adelaide (Ph. (08) 830 34014, Fax(08) 830 33417, email helen.malby@adelaide.edu.au)

APPLICATION FOR ETHICAL APPROVAL OF PROJECT INVOLVING HUMAN SUBJECTS - COVER SHEET - SUMMARISING PROTOCOL & INCLUDING INVESTIGATORS' SIGNATURES

Please attach this to the front of the application

<p>APPLICANT Name include title Professor/Dr/Ms/Mr and Position</p> <p><i>Prof. Anthony Francis Worsley</i></p>
<p>DEPARTMENT including campus/institution contact address</p> <p><i>Dept Public Health (R. A .H. Bice Building)</i></p>
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<p>OTHERS INVOLVED</p> <p><i>Mr Thomas A Laws / Dept. of Public Health/ Masters upgrade to PhD</i></p> <p>If this is a student project please indicate name/department/candidature</p>
<p>PROJECT TITLE</p> <p><i>Health Practices of Men within Dual Income Families in South Australia</i></p>
<p>LOCATION OF RESEARCH <i>Adelaide Metropolitan area</i></p> <p>DATE PROJECT TO BEGIN <i>November 15 2000</i></p> <p>ESTIMATED DURATION OF PROJECT <i>Six months</i></p> <p>SOURCE OF FUNDING <i>National Pharmacies</i></p>
<p>AIMS OF PROJECT please give concise description in lay terms</p> <ul style="list-style-type: none"> • <i>To identify the type of health care provided by men living in dual income families and to describe those practices.</i> • <i>To quantify the type of health care provided by men for family members</i> • <i>To inform health professionals and policy makers of the experiences of men providing health care for their family, the issues they endure and what practical help and support is needed to help overcome limitations to their contributions.</i>

ETHICAL IMPLICATIONS OF PROJECT

Focus groups (approximately 3-4) containing 3-10 men will be conducted to create and validate survey questions. The men will be informed (a) on the purpose of the interviews and the aim of the study. (b) that the interviews are not designed to be therapeutic. (c) their participation is voluntary and that they may withdraw without question at any time from the interview process.

A survey questionnaire addressed to 'men in the house' will be mailed, on a random basis, to participants. As per policy 13.1 Questionnaires, The survey is a straightforward exercise in eliciting information, where the intention is to gather the facts and is unexceptional. There will be no "trick questions"

- ◆ *The men will be informed that filling out and returning the questionnaire will be a voluntary action*
- ◆ *Those participating will be informed that the information they provide will remain confidential*

PLAN/DESIGN OF PROJECT brief description in lay terms

A questionnaire will be forwarded by mail to men living in households within the Adelaide Metropolitan area.

Households will be randomly selected

Men living in dual income families will be asked to return a completed questionnaire

A follow up letter will be sent to those who do not reply requesting that they participate

Quantitative data will be analysed to identify what health care activities men have performed

Qualitative data will be used to provide descriptions of men's health care activities and analysed for themes emerging from men's experiences of providing care

DRUGS

Will drugs be administered to subjects?	NO
• If so give name of drug(s)	
• Dosage:	
• Method of administration	
Is the administration for therapeutic purposes?	N/A
Will the project be conducted under the	
Clinical Trials Notification (CTN) Scheme?	N/A
Clinical Trials Exemption (CTX) Scheme?	N/A
Is Commonwealth Department of Health permission required?	NO
If so, has permission been obtained?	N/A

SUBJECTS

- Source:
Random selection of metropolitan South Australian households

- Age range:
16-80 years

- Selection criteria:
Men living in dual income families that contain children

- Exclusion criteria
Men not living in dual income families

SIGNATURE OF ALL INVESTIGATORS NAMED IN THE PROTOCOL

Tom Laws

Prof. Anthony Francis Worsley

Date *October 5, 2000* |

APPENDIX 8: Journal article – Father's struggling for relevance in the care of their terminally ill child

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Fathers struggling for relevance in the care of their terminally ill child

ABSTRACT

Children with terminal illness receive substantial amounts of care from their parents within their home, a palliative care facility or general hospital. Whilst there is a long history of research exploring child and family experiences and coping styles within these settings, the focus has not been on fathers' participation in care-giving. This phenomenon can be explained by traditional sex-role socialisations whereby men are ostensibly conditioned as breadwinners and mothers remain embedded as the primary carers for children, particularly when illness arises. Nevertheless, nurses report that men do provide direct care-giving or seek to be more involved in caring for their child. This literature review offers opportunities for health professionals to reflect on the significance of gender in parenting the terminally ill child and to develop empathy for men experiencing difficulties in their role as care-givers. As there is little literature available on this topic, this paper portrays men's experiences and importantly the barriers they encounter in meeting their desire to care. The approach provides a suitable basis for developing a research agenda to promote competencies and relevance for fathers in their role as care-giver.

KEY WORDS

care giving; male participation; child health; fathers' needs; competency promotion; role barriers; literature review; research agenda

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daughter by contributing directly to their care. Although many men are involved in care-giving or aspire to be more involved, there is little literature that identifies their experiences. Consequently, these men are likely to have needs that are largely unrecognised or unmet. On this point Brown & Barbarin (1996: 55) contend that:

INTRODUCTION

This work is premised on the notion that the father of a terminally ill child will want to optimise the quality of life for their son or

While existing research yields much about mothers, the needs, concerns and experiences of fathers are rarely studied and are not well understood.

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Difficulties and barriers encountered by men in providing care to a sick child must be identified in order to develop their care-giving competencies and promote their role as a care-giver. Although the following statement made by Holm et al. (2003: 312) was prompted by a single comment made by one mother in their study, it has intrinsic meaning to both parents and carries an essential request from them to all health professionals:

... parents want nurses and other medical professionals to help socialize them into actively participating in their children's medical care. (Holm et al. 2003: 312)

Referring to men's ability to support their child during medical procedures and treatments McGrath and Huff (2003b: 9) stated that:

There has been a modicum of work published on the father's perspective and even less on father's hospital experience, particularly in relation to their involvement with invasive treatment procedure.

Nurses and health workers who wish to develop strategies to support fathers should be aware of the gaps in the literature and the need to develop evidence on which to base their practice. McGrath & Huff (2003b) provide evidence to show that fathers have different needs to mothers, carry out care differently and bring important strengths to their role as parents within hospitals.

To identify the ways in which men participate in and find relevance in caring for their terminally ill child a literature search was conducted using the data base Cumulative Index of Nursing and Allied Health Literature (CINAHL). This database was seen as primary because nurses and other health professionals are the most intimately involved in assessing and providing resources for care giving, teaching care-giving skills and providing emotional support. Whilst literature from other social sciences is evidenced in this paper it was found that much of

that content focused on role identification, psychological reactions to stressors caused by changes to family dynamics following the diagnosis and adjustments to death of a child, are only brief or isolated comments concerning men's practices surround care-giving.

THE GRAVELY ILL ADOLESCENT

There is scant literature concerned with caring for the gravely ill adolescent. Presumably this is because very few adolescents develop a terminal illness. A majority of adolescent deaths occur through accidents and suicides. Using CINAHL (1984–2004) and the combination of the key words 'adolescence' and 'cancer' resulted in 169 hits. A wide range of topics re-emerged and a review of abstracts revealed few prominent themes. For example, several articles focused on the child's response to a parent with cancer, others related to sibling adaptation, child–parent separation relating to the stressors of coping with a child's terminal illness and the psychological impact of the diagnosis of cancer on parents. Importantly, the vast majority of articles were not concerned with the relevance of paternal care-giving. Of significance were numerous abstracts highlighting that little was known about fathers. For example, Chesler & Parry (2001) assert that:

Despite a proliferation of research with families of children with cancer and gender differences in parental coping, few studies have explicitly explored the experiences of fathers of children with cancer.

McGrath & Huff (2003a: 41), referencing to a two part discussion on fathers' experience of and role in treatment of leukaemia, maintain that:

There is scant work completed on the fathers' experience with the treatment for childhood cancer' and 'most of the research to date only focuses on maternal issues and

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data collection involves predominantly a response from the mother.'

Aiming to describe uncertainty experienced by and coping patterns of fathers, of children with a diagnosis of cancer Sterken (1996) declares:

Limited research has been conducted regarding the father's relationship with the chronically ill child, particularly the child with cancer.

As support for their research on fathers' understandings of the efficacy of clinical research conducted on their children Liaschenko & Underwood (2001: 71) purport that:

Fathers, of chronically ill children are not well represented in the literature, and we know even less about fathers whose children are involved in clinical research.

This lack of data on fathers was commonly attributed to a researchers focusing on mothers. For example, in a pilot study containing data from fathers of school aged children vis a vis a family member with cancer, Kirsch & Brandt (2002: 73) state:

Collecting data from fathers has been an ongoing problem for researchers interested in developing a comprehensive view ...

Jones & Neil-Urban (2003) as a prelude to a secondary analysis of their data, state:

Caring for a child with cancer is a demanding experience for both parents, yet most research focuses on mothers (2003: 41).

Using a phenomenological approach, Hayout & Krulik (1999) who studied 11 Israeli families over two and a half years, openly declared:

This article presents partial findings from a study that examined the process experienced by parents (mainly mothers) [original emphasis within the abstract] of an adolescent child with terminal cancer.

As an introduction to their research report on their study of gender differences in parenting a child with cancer Brown & Barbarin (1996) raise the issue that, if men parent differently why is there an assumption that only mothers should be researched?

Little is known about the emotional and behavioural responses of parenting a chronically ill child. In fact, in much of the literature on parenting chronically ill children, 'parent' is often equated with 'mother'. However, we know that considerable differences exist in the ways males and females carry out the parental role (1996: 55).

Notably, the vast majority of literature pertaining to the care of the gravely ill child and the dying child refers to 'parents'. Few researchers disaggregate their data into findings for mothers and fathers. Consequently, fathers are rarely discussed as a separate entity with respect to their contribution to care. This is in contrast to the care provided by a mother, which is often specifically referred to in the literature. Laws (2003), in a critique of Young et al.'s (2003) work concerning how information about cancer is communicated from parent to children, makes the point that researchers should not report their findings on the basis of a single category, that of parent. Summarising data in this way assumes that mothers and fathers are homogenous and denies there are differences between the sexes. The argument for disaggregating the data into maternal and paternal themes and actions is based on the broad understanding, held by those researching gender, that masculinity causes men perceive and action health differently to women. Therefore, men's interactions with their children on the topic of health and illness, is likely to differ from that of a mother.

The quotations set out above are important cautionary notes from authors to readers with the intent of highlighting a lack of data available

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to address a wide variety of research questions/issues vis a vis paternal care of a child with a terminal illness. Further, none of the literature, when reviewed in its entirety, was concerned with the health practices fathers towards their terminally ill child. Congruent with this finding is the opening comment by Holm et al. (2003) in their recent work on identifying gaps in the literature relative to parental participation in care.

Few research studies have addressed the ways parents participate in their child's medical care, particularly in relation to the cancer experience (2003: 301).

and

Although studies have addressed parent behaviour during specific, well defined procedures that are part of cancer treatment, research has not focused on parents' descriptions of ways they participate more broadly in the entire process of their children's medical care, beginning with their search for diagnosis and extending through the completion of treatment. (Holm et al. 2003: 302)

Although Holm et al. (2003) provide rich qualitative data there are few excerpts from their interviews with fathers and these pertain to only one task: gathering information about the illness and treatments (e.g. internet use and questioning the medical profession). There was no data on direct care-giving. The same can be said Brown & Barbarin's study of gender differences in caring. Their analysis was limited to 'dealing with medical aspects' with no reference to care-giving practices. Katz & Krulik (1999), using 6 questionnaires, performed a comparative analysis of fathers' experiences of caring for a child with a chronic illness ($n = 80$) and those men caring for a child without such illness ($n = 80$). The main finding was that experiences were 'fairly similar' between the groups of fathers with the main differences reflected on the variables of stressful life events

and self-esteem. There was no linkage made between any of the variables tested and paternal care-giving.


THE GRAVELY ILL CHILD

Once a child has been diagnosed as having a terminal illness, parents are confronted with the task of having to decide at what point the 'burdens of treatment' are outweighed by the potential benefits, especially if the likelihood of benefit is low. Fleischman et al. (1994) conclude that, whilst there is 'extensive literature' discussing medical and parental decision making in relation to the seriously ill new-born, 'inadequate attention' has been paid to identifying the appropriate means for caring for gravely ill children of all ages and 'managing' their death. Goldman (1996) and Fleischman (1994) maintain that as a consequence of the scant research data about the dying child and appropriate management practices, numerous unresolved issues remain for both parents and health workers.

There is little literature describing men's role in caring for their dying child. Black (1998: 1376) offers an explanation:

Mothers, more than fathers are involved in nursing and caring for dying children and have therefore been more extensively studied.

On the point of direct care-giving, Dalley (1988) explains that men hold the ideology of 'caring about' rather than 'caring for' family members. This ideology is widely supported in society by men and women. However, the extent of parental involvement should not be used as a means of justifying women as a research focus, given that men experience strong emotional reactions in response to the news that their child is gravely ill. Whilst there have been several studies measuring the emotional adjustments of parents who are caring for dying children, the data relates to parents, and

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does not disaggregate to allow for measurement of the level of adjustment for mothers and fathers separately (Mulhern et al. 1983; Lauer et al. 1983; Kupts 1986). Black (1998) and Schwab (1992) identified some men as being concerned that their spouse was 'overly preoccupied' with the death of the child. In a study of the emotional impact of having a child dying of leukemia, Binger & Ablin (1969) mention fathers, but only to note that they are absent from direct care of the child. The absence is explained in terms of a coping mechanism; fathers remove themselves from management of the dying process to avoid the immense emotional pain that it evokes in them. In an account of 'single parents' experiences of caring for a dying child, Gillis (1986) was concerned only with mothers.

MEN'S CONTRIBUTION TO CARE-GIVING BY TREATMENT SETTING

The news that a family member has been diagnosed with a terminal illness, and the events leading up to their death, represent a significant juncture in the life experiences of most families. Literature from a number of disciplines identifies problems experienced by families from the time of diagnosis through to care of the dying and the period of grief that follows. The nursing literature in particular that describes the family's contribution to care. Cook (1984) conducted a study of parents of 92 gravely ill children who were treated for cancer of the blood and died during the years 1975 through to 1979. The study by Cook (1984), based on interviews with parents from 1980–81, was conducted two decades ago, yet remains a key reference for contemporary works (e.g. Black 1998; McGrath & Huff 2003a) because it is the first to investigate specifically how *gender* shapes the way in which both men and women care for a gravely ill child. Even as late as 2003, McGrath & Huff (2003a: 6) contend that there has been a 'lack of previous works including fathers' and that in

relation to their study 'This sample is seen as making an important, albeit preliminary contribution'.


There is a longstanding debate among health professionals concerning the appropriate means of caring for the terminally ill child or adolescent, and what is likely to be the best treatment setting. There are several treatment settings in which care is provided; in particular, the acute care *hospital*, the *hospice* (specialising in palliative care) and the person's *home*. The choice of treatment setting is influenced by the patient's wishes, the probability that continued treatment will prolong life hope, and the family's ability to cope and contribute to the care of the dying (Lauer et al. 1986; Darbyshire et al. 1997).

Hospital care

For men, the hospitalisation of their terminally ill child severely reduces the number of opportunities available to them to be with and provide care for their child. Cook (1984), in a study of the experiences of parents of terminally ill children, concludes that there are fewer opportunities for men to care for their child in hospital. This is attributed to the traditional gender division of labour.

... 'cure' became a valued activity done by men, 'care' became the domain of women, thus undervalued and under compensated. 'Care' remains invisible, priceless in health institutions as well as at home, and those who provide it remain socially unconsidered and unknown. (Robinson 1997: 244)

Women see it as their role to be with their gravely ill child, and men see it as their role to support the mother and the rest of the family. Specifically, Cook (1984) found that women are more likely to spend the night in hospital with the ill child, whilst men took on the responsibility of caring for the ill child's siblings, home duties, and communicating news to relatives. Black (1998: 1377) also contends that, whilst

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the mother provides care in hospital, the father 'tries to keep the rest of the family going and earn a living'. As a consequence of their differential involvement with the child's illness and with other family members, men and women experience the associated problems differently. For example, what mothers do in relation to caring for a child with a prolonged illness, and the effects of their labour on their personal physical and mental health, are well accounted for in the literature (Cook 1984; Burton 1975). Conversely, men experience the tension between fulfilling their work commitments and wanting to be with their ill child (Cook 1984).

The literature suggests that, aside from work commitments, fathers face other barriers that prevent them being with their child. The time men spend with their ill child is often the residue of time remaining after they have chauffeured children, worked, cooked, done the housework and commuted to and from the hospital. Cook (1984) and McGrath and Huff (2003b) both noted that men often spent the weekend in hospital with their child as a means of relieving the mother and allowing her to spend time with the rest of the family at home. The distance between home and hospital was often substantial in rural areas, which could further constrain the time available for fathers to spend with their ill child. Of the 92 children in Cook's (1984) study, 75 died in or on the way to hospital. No account was provided of the fathers' ability to be there at the time of death.

Many mothers take the view that men are simply 'uncomfortable hospital visitors' who disliked the hospital environment (Cook, 1984; McGrath & Huff, 2003b). The fathers, who are mostly absent from day-to-day observations of their child's progress have fewer opportunities to confer on decisions with medical personnel and express the feeling of being 'left out' of their child's care and life. Cook (1984) found that fathers held specific ideas about why they felt unsupported, believing that:

... physicians and nurses were not as concerned about or helpful to them as they were to the mothers and children... In other cases, the wives or other family members made the father feel excluded ('She shut me out'). One father described his situation this way: 'I felt left out. I felt that my wife became closer to her family and further from me.... I resented her mother for always being there. I felt like a fifth wheel or something. (Cook 1984: 83)

It is likely that a lack of nexus between hospital staff and fathers, along with tensions created by the gender division of labour centering on who should care has detracted from the fathers' ability to appreciate what little time they have with their ill child. McGrath & Huff (2003b) found that lack of privacy, lack of role models and the inability of fathers to share the experience with other parents through intimate conversation exacerbated the discomfort fathers experienced in hospital. Fletcher (2004), through his work with fathers in an intensive care unit in New South Wales has moved some way to identifying and rectifying this problem. Unfortunately, the impetus for this support programme came more from the stress felt by fathers than being based on an assessment of fathers' needs:

We were called into that unit because one of the dads lost his temper... so they (staff) knew this dad, this dad exploded. They called the police. The staff were very upset. But when they talked through the issue the staff realised that, for the fathers in the unit there was no role ... like the mothers had a role the staff new what they were doing. But the dads seemed to spend most of their time looking at the monitors and the technical equipment. (Fletcher, 2004)

The above indicates that a more structured approach to assessing the needs of fathers and strategies to support their role should be developed.

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Hospice care

A major issue for parents, doctors and nurses concerns the type and quality of care offered to terminally ill children in differing settings. The World Health Organisation (2004) considers *palliative care* as the 'gold standard' by which all other forms of care for the dying is compared. It is:

... the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. (Davies & Steele 1996)

Whilst there is a substantial body of literature on adults receiving palliative care, there is no comparable literature for children who are gravely ill:

The growth of palliative care medicine for adults has not been paralleled in pediatrics. It is not just that death is less common among children than adults. The dying child has been avoided in the literature, perhaps for emotionally charged reasons. (Liben 1996: 24)

Goldman (1996) attributes a lack of knowledge to the difficulties experienced in gathering epidemiological data, and to the small number of children, relative to adults, in need of palliative care. Frager (1996) and Farrell & Sutherland (1998) also report that the proportion of children receiving palliative care in a hospice setting is low.


In principle, palliative care can be offered in a hospice, in a hospital setting, or in the home. However, in the United Kingdom there is ongoing debate as to the ability of the health system to provide 'seamless care' when children are transferred from health centers focusing on a 'cure' to a hospice that focuses on providing 'palliative care' (Farrell & Sutherland, 1998). Further, medical staff who work in specialist

paediatric units are reluctant to move children to hospice units because they are skeptical about the purported benefits to be gained from establishing children's *hospice services* (Farrell & Sutherland, 1998). In an international review of palliative care for children, Martinson (1996) contends 'there are too few referrals to home or hospice care for children'. Lack of referral was attributed to the inability of the health professionals to convince parents of the need for this type of care. In an Australian study, Darbyshire et al. (1997: 26) concluded that:

Their [the parents] prior knowledge of palliative care philosophies and services were minimal and thus the need and desire for information was great.

However, a systematic assessment of parent's level of satisfaction with the information they received was not forthcoming. Concerns have also been advanced about the ability of health care workers to provide continuity of care and support for children and their parents when they are transferred from health services to *home care* (Farrell & Sutherland, 1998). They ask: how well equipped are nurses and other allied health professionals to support parents in their development of nursing skills, gain mastery of complex equipment and safely administer medications, by a range of routes? According to Farrell & Sutherland (1998), such an assessment has not yet been undertaken.

Perhaps the most important consideration for parents, who opt for home care, is that their child will have access to effective and reliable means of pain relief. Numerous authors identify a correlation between parental distress, caused by their child suffering from intractable pain and a lack of literature supporting appropriate pain management practices within the home (Frager 1996; Liben & Martinson 1996; Collins 1998). Lauer (1986) estimated that nearly 40% of families providing home care returned their child to hospital to die because they were overwhelmed

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by problems associated with care related problems. For example, there was a positive relationship between the frequency of re-hospitalisation, and inadequate pain relief and general symptom management. The acquisition of competencies and development of effective skills for managing such problems demands major time commitment and expertise from the care giver(s). Importantly, an analysis of what fathers see as difficulties in achieving the desired level and type of care-giving skills is ostensibly absent from the literature. Darbyshire et al. (1997: 27) provides a useful insight into the complexity of care-giving as perceived by fathers.

Father: I guess our immediate needs weren't so defined, it was difficult to know exactly, it's just all, all the support you need at home, thinking sort of what, I mean, how big a support, how big a resource is it [palliative care] you know? What does it really do and what really happens? So the practicalities of what it was about weren't clear to me at that stage but then at the same time I mean the need for it wasn't so imminent either. It was just that you know, we could go home, and the support would be there.

The part that men play in deciding which treatment setting is the best for their child has yet to be explored. However, it can be assumed that their wives/partners have the final say because they are the primary care givers (Cook 1984; Black 1998; Dalley 1988).

The home

In the situation where a child is suffering from a life threatening illness and a prolonged inexorable decline in health is expected, home care is deemed an appropriate means of promoting the child's well being. There are also obvious practical and financial advantages (Lauer et al. 1983; Mulhern et al. 1983). In a cost analysis of home care, Chochinov & Kristjanson (1999) conclude that care becomes more expensive with distance from the home setting. Parents

providing home care reported fewer disruptions in family routine and more control over their child's care than did parents who were not providing home care (Lauer et al. 1983: 111). With respect to the level of parental involvement in care, Goldman (1996: 16) contends that:

When a child is to be cared for at home, the parents and the sick child themselves should take an active part in planning a practical and acceptable regimen of care.

However, Cook (1984) found that women were more likely to 'clear their schedules' in order to spend more time caring for the ill child, whereas men tended to continue with their normal work routine and civic duties. However, men's opportunities to care for their gravely ill child are substantially affected by the expectation of others (1984: 72):

Fathers are expected to control their emotions – to play a stoic role – and to continue their duties as economic provider.

Further, employers are reluctant to give men time off during their child's illness (1984: 82):

Other men found that, although their employers formally consented to giving them time off, informally they did not approve of such behaviour and saw the care of the sick child as a 'mother's job'.

McGrath (2001) also found that work commitments created major obstacles that effectively thwarted most fathers. Nevertheless, in a later publication McGrath & Huff (2003a) revealed that a continuum of care-giving existed, with some fathers seeing work as a welcome break from the tensions, hospital visits and overnight stays, to other fathers who adopted a full-time commitment to in-hospital care-giving.

PARENTS' SATISFACTION WITH CARE ARRANGEMENTS

Quantifying parents' level of satisfaction with

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home care has been problematic. Lauer et al. (1983) acknowledge that a longitudinal study, randomising families into potential home-care or non home-care groups, would be the best method of providing evidence to show differential rates of parental satisfaction (before and after the death of a child). However, such a procedure would present 'serious ethical and practical problems' (Lauer et al. 1983: 110). In consideration of this, Lauer et al. (1983) and Mulhern et al. (1983) used convenience samples to study parental and sibling adaptation following the death of a child. Although these studies showed that men were included in the sample, neither study disaggregated the data to provide a father's perspective. Both studies concluded that the 'parents' and siblings of children who had died in home care had fewer marital problems and less intense feelings of guilt than families experiencing hospital care. However, as there are variations in family characteristics and personalities Mulhern et al. (1983) suggests that all families be counseled as to 'their choice of care for their terminally ill child and its anticipated psychological risks and benefits' Mulhern et al. (1983: 747). Darbyshire et al. (1997: 29) provides a rare insight into one father's preference for home care in relation 'post death events'.

Father: I think it was more comfortable being here [home] than say being in the hospital (...) if perhaps we'd stayed in the hospital it might have been awkward after he died or something. When you, I was told, I remember hearing that there was a, you know, we could stay, there was a room you could be moved to or whatever, but I guess there is always the feeling of you're in an unfamiliar environment and a concept that perhaps you can't hang around too long or you, you should move off, or if [you] go out you, you know, you can't just sort of come back as you like. Whereas when Oliver died we decided to leave him here [home] overnight and asked the funeral director to call the next morning to pick him

up and I think that having that opportunity, which was you know, another fifteen or sixteen hours later, was something that we wouldn't have had perhaps.

MEN'S CONTRIBUTION TO THE SUPPORT OF OTHERS


The ways in which men contribute to the support of their spouse/partner whilst she is caring for a gravely ill child has been largely unreported. However, several studies do suggest that some men either withdraw from caring or exhibit aberrant behavior (Cook 1984; Sabbeth 1984; McGrath & Huff 2003b). Sabbeth & Leventhal (1984), in a review of 34 studies concerned with marital adjustment in response to caring for a child with a prolonged illness, found that control groups were seldom employed in the research. Areas of marital adjustment that received almost no attention from the researchers include 'communication, decision making, and role flexibility' between mothers and fathers of a child suffering prolonged illness (Sabbeth & Leventhal 1984). Chao-HsingY (2002), in an overview of the literature prior to studying the differential response by parents to similar stressors concluded that:

To date, few studies have been reported that explain why some aspects of stress related to a child's illness are higher for mothers and others are higher for fathers, when parent couples encounter the same stress.

and

Reports published over the last few decades present contradictory findings about the psychological distress and coping patterns of parents whose children have cancer. (Chao-HsingY 2002: 599)

Cook (1984: 79) found that some men were far from supportive of their wife's role as caregiver, claiming that men showed 'resentment of the amount of time they spent with the will

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child'. Those men coped with the resentment by increasing their consumption of alcohol and acted out their frustrations by 'threatening or aggressive behavior, drug usage, or extramarital sexual activity' (Cook 1984: 80). McGrath & Huff (2003b), report that many men in their study coped with being separated from their wife/partner, due to care-giving commitments, by using humor. For example, many men referred to romance 'being put on hold'. Another problem frequently described by the women in Cook's study (1984) was that their husbands withdrew from them emotionally. The husband's withdrawal of support made the wives feel angry because it left the management of the final stages of the child's illness completely in their hands. It also made them feel 'abandoned' at the time when they needed the support of their husbands the most.

The extent to which men provide physical and emotional support for the siblings of a gravely ill child has been largely unreported. Yet Black (1998) states that siblings of dying children face approximately double the risk of developing psychological disturbance, compared to those who have not had this experience. McGrath & Huff (2003a: 8) report that some fathers:

express an awareness of the needs of the sibling and how the well children in the family can be negatively affected by the medical drama.

Although there was no in-depth analysis of children's responses the researchers concluded, from parental comments, that siblings were grieved by their separation from fathers as well as mothers as they alternated hospital visits.

Mulhern et al. (1983: 743) focuses specifically on the effects of the death of a child stating:


In approximately 50% of bereaved families, at least one member receives psychiatric care precipitated by the child's death ...and

approximately 25% to 50% of surviving siblings experience significant emotional, behavioral, or academic adjustment difficulties. Pathologic grief reactions, clinical depression, and psychosomatic illnesses are commonplace as well.

However, most studies have not looked at the long-term effects of sibling death. Whether or not fathers recognise the risk of mental health problems for the siblings and attempt to help them adjust is not reported in the research literature. Black (1998: 316) recommends that health professionals should find the time to make regular visits, to review 'the functioning of each family member'.

CONCLUSION

In summary, there is no definitive work that systematically sets out that fathers are the parent least researched vis-a-vis their role and relevance to care-giving for a terminally ill child. However, those researching within families of gravely ill children find it necessary to highlight that men are not or have not been the focus of this area of research. Those men that do not provide care because they remain constrained by work commitments are unlikely to appear in such studies. From the literature reported in this paper, it is evident that some fathers desire to and do care for their child directly, as well as supporting their family and spouse/partner in their caring role and experiences. It appears that these men face substantial barriers to effecting direct care. The hospital environment and a limited nexus between men and hospital staff are cited as the main barriers to men achieving well supported and fulfilling care-giving (Cook 1984; Fletcher 2004). Yet some men wish to develop skills to care competently for their child and to share their experiences with others in a similar situation/role. There is some evidence that men need personal space to work through issues arising from their desire to care, the barriers they encounter, and to take

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part in decision-making surrounding children's treatment options.

This review provides a foundation for developing research strategies to raise nurse awareness of the issues surrounding fathers caring for the terminally ill child. Improved knowledge will encourage nurses to learn more about these men and be better able to develop practice strategies to assist them. Fathers, with better support for and understanding of their emotional reactions and knowledge of care options, could be more effectively involved in providing direct care for their child and in so doing provide the mother with valuable respite. Further, men's lives would stand to be enriched by being valued as a carer.

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Amendments

All typographical errors were amended and appear in the updated PDF file submitted for electronic thesis publication.

Examiner one:

Chapter four: Contemporary references required: These were added alongside Stearns, (1991); they are - Lamb, (2000); Rohner & Veneziano , (2001).

Chapter five: Why use only rural men in discussion groups? Metropolitan men did take part in individual interviews; as was stated in the thesis “ ... *the issue of acquaintanceship did not appear in another rural group discussion or the metropolitan locations.*” The examiner requested a precedent. Here is an explanation for the use of individual interviews with metropolitan men. Parker and Tritter (2006), contend that what counts is “generating in-depth discussion via a logical sequence of open-ended question”, irrespective of whether the interview was one-to-one or a group discussion.

Examiner two

The abstract needs to be laid out in a a more conventional style –

Response from candidate – as this study had multiple methods a conventional abstract was not applicable; this position is supported by Thomas SA (2000) *How to write health Sciences Papers, Dissertations and Theses*, Chapter 11: The function of the abstract, Churchill Livingstone, China. P93.

Suggested for “further work” by the examiner was a more detailed approach to the socialisation of boys. This recommendation has been noted and I thank the examiner for the detail and feedback on this point.

The examiner identified a reference to a small reflective chapter titled “on becoming involved” – this chapter was deleted in the final stage of the thesis because of length of the document – all reference to this has been removed without affecting the integrity of the thesis.

The examiner questions the amount of details provided in the method section for a systematic review of the literature – The author of the thesis stated it was a systematic search (not a systematic review).

The examiner used the word ‘shame’ that there was such a reliance on quotations – a series of quotations was used as evidence, from other authors that had recognised gaps in the literature; a mere summary statement that a score of authors had recognised a lack of information on fathers would not have been as powerful as their actual published statements.

Details on the prevalence of childhood conditions “may not have added to the study” These were necessary justification for my choice of illnesses.

As recommended, **the abstract now identifies that ‘new knowledge’ was produced** “*This study used several methods of data collection that ultimately identified new knowledge of men’s health practices not previously recorded in the literature.*” And whilst the examiner asked this to be emphasised in the conclusion this information did appear in the submitted thesis (I have added the word ‘new’). “*Men in the focus groups described a repertoire of health practices they had performed that went far beyond any found in the literature. “This new knowledge of actual health practices performed by men toward their children, the frequency of these practices and repertoire of skills, are important items for determining the extent to which fathers are adopting a new gender role.”*”