

**THE MOTHERHOOD CHOICE:
DEVELOPMENT AND EVALUATION OF A
DECISION AID FOR WOMEN
WITH MULTIPLE SCLEROSIS**

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Presentation of Thesis

This thesis is presented as a series of **published/submitted** manuscripts. The first chapter contains a review of the literature, introducing the research rationale, aims and hypotheses. Chapters two, three, four and five contain the following manuscripts. The candidate is the principle author of each of these papers.

- Chapter Two: Sponiar, M.C., Sharpe, L., Butow, P., Fulcher, G. (2007)
Reproductive Choices of Women with Multiple Sclerosis. *International Journal of MS Care*, 9, 9-12.
- Chapter Three: Prunty^{*}, M.C., Sharpe, L., Butow, P., Fulcher, G. (in press)
The Motherhood Choice: Themes Arising in the Decision-Making Process for Women with Multiple Sclerosis. *Multiple Sclerosis*.
- Chapter Four: Prunty, M.C., Sharpe, L., Butow, P., Fulcher, G. (in press). The Motherhood Choice: A Decision Aid for Women with MS. *Patient Education and Counseling*.
- Chapter Five: The Motherhood Decision Aid: Mechanisms of Treatment.
(submitted to *Patient Education and Counseling* August 2007).

The final chapter provides a summary and conclusions of the research findings, limitations and suggestions for the direction of future research.

The study presented in this thesis represents research undertaken by the candidate in conjunction with other researchers in the Clinical Psychology Unit and the Medical Psychology Research Unit at the University of Sydney, and the Multiple Sclerosis

* Candidate's married name

Societies of New South Wales and Victoria. Ethics approval was granted by the University of Sydney as well as Multiple Sclerosis Australia.

The candidate was involved in all aspects of the study, and was responsible for coordinating the study under the supervision of Associate Professor Louise Sharpe, and associate supervision of Professor Phyllis Butow and Dr Gary Fulcher.

The contributions of the candidate include:

Study design: The candidate was responsible for identifying the topic, recruiting the study sample beginning with the large-scale mail-out to 1410 female members of the MS Society in New South Wales and Victoria, Australia. The candidate designed the initial preliminary decision aid and ran the focus groups in the qualitative study. The candidate selected the questionnaire measures and compiled the demographic questions and the knowledge questionnaire.

Data collection, entry and analyses: The candidate was responsible for all aspects of data collection, entry and analyses. The candidate formulated the hypotheses. All data presented in this thesis was analysed by the candidate under the guidance of Associate Professor Louise Sharpe.

Manuscripts: The candidate was the principle author and wrote all first drafts of the manuscripts presented in this thesis, responsible for the conceptualisation and the interpretation of the data, under the supervision of Associate Professor Louise Sharpe and Professor Phyllis Butow.

Abstract

Multiple sclerosis (MS) is the most common neurological disease affecting young adults. MS affects approximately 1 in 1000 people and, like other autoimmune diseases, women are more likely to be affected than men. The illness typically onsets between the ages of 20 and 40, and hence usually affects women of child-bearing age. The course of the MS is often unclear for years after diagnosis and since most women are diagnosed in their child-bearing years, they often have to make reproductive choices before their prognosis is clear and while the future remains uncertain.

For women with MS, starting a family is an individual choice that needs to balance the importance of motherhood for the woman and her partner against the risks that she will be unable to care for the infant or child as a result of increasing disability. In other areas of medicine where finely balanced decisions are required, there has been a recent proliferation of decision aids that aim to inform people of the benefits and risks of opposing courses of action. In addition, decision aids help patients to weigh their values against the risks and benefits to make an informed decision. Despite the existence of over 200 decision aids to help patients consider decisions related to their medical conditions, not one exists that deals with the decision of whether or not to have a family for women with a chronic disability, such as MS.

This thesis developed and evaluated a decision aid for women with MS to help them decide whether to start, forego or enlarge their families. The study utilised the criteria set out for the development of decision aids, according to the Cochrane Systematic Review of Patient Decision Aids (O'Connor et al., 2003). The first aim was to determine the proportion of women who are undecided about the motherhood choice

and for whom a decision aid may be relevant. Results found that the motherhood choice was relevant to 46% of the women who responded to an initial mail-out.

The second study aimed to establish women's current concerns and thoughts regarding pregnancy and motherhood, and their response to the pilot decision aid. Twenty women participated in qualitative interviews and results supported previous findings that the mother's health concerns, coping with parenting and societal attitudes are significant concerns when considering this decision. This study further identified concerns from different groups that had a direct impact on the decision to have children, including the experience of parenting, the child's well-being and the timing and pressure of the decision.

The main study was a randomised controlled trial of the decision aid aiming to determine whether the decision aid facilitated decision-making in women with MS. The study confirmed that the decision aid presented a balanced view to women, increased knowledge, reduced decisional conflict, increased decisional self-efficacy and certainty of the decision, and was free from adverse effects on psychopathology.

The final component of the study was a 12 month follow-up which aimed to explore the long-term effectiveness of the decision aid and what aspects were valued by the women who received it. It was found that over time, women in the intervention group did maintain their certainty, but women in the control group also became more certain of their choice. At follow-up, the difference in certainty was no longer significant between the two groups. However, women did report that the intervention was useful in (a) providing access to information previously unavailable or difficult to obtain, (b)

facilitating communication between women, their partners and health care professionals, (c) aiding them in considering and utilising their networks of support, and (d) preparing them for potential difficulties.

In summary, this thesis developed and evaluated a decision aid for women with MS who are considering motherhood. The results showed that many women were undecided and, in the absence of good information on the topic, many women had concerns about pregnancy and parenthood. The decision aid was shown to be effective across a range of measures and free from adverse psychological effects. Hence, this is evidence-based resource can now be recommended for those women with MS who are currently contemplating motherhood.

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