

Perspectives of Women with Chronic Inflammatory Diseases in Australia on Their Journey to Motherhood

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OBJECTIVE

- To explore the perspectives of women with chronic inflammatory diseases in Australia regarding disease management and pregnancy.

BACKGROUND

- The onset and diagnosis of chronic inflammatory disease (CID, rheumatoid arthritis [RA], psoriatic arthritis [PsA], ankylosing spondylitis [AS], psoriasis [PsO]) in women often overlap with their peak reproductive years.¹
- Despite evidence-based treatment recommendations for the management of women with chronic rheumatic disease,² women in Europe continue to have fears and misconceptions, owing to the lack of information available to make informed, confident treatment decisions around family planning.³ Similar perspectives amongst women have been reported in the US and Asia-Pacific region.^{3,4}
- It is unclear if women with CIDs in Australia receive adequate and timely information from healthcare professionals (HCPs) to feel appropriately supported when making treatment decisions around family planning.

METHODS

- A 20-minute online survey was conducted by Hummingbird Insight from September to November 2018 in Australia.
- Participants were women (18–45 years) who had self-reported moderate to severe CID, who were not currently pregnant but had been pregnant in the past 2–5 years, and had received medication for their disease.

RESULTS

- 135 women participated in the survey (RA=51; AS=30; PsA=27; PsO=27) and 64% reported their CID to be moderate; 36% reported severe CID.
- 53% of the women were on anti-tumour necrosis factors (anti-TNFs); 17% were on other biologics (e.g., tocilizumab, rituximab); 50% were on non-biologic disease modifying antirheumatic drugs, excluding methotrexate; 19% were on methotrexate.
- Before Pregnancy**
 - During their most recent pregnancy, 32% of women were actively trying to conceive; 64% were open to seeing what happened/not thinking about pregnancy; 4% were actively trying not to conceive.
 - 46% delayed pregnancy; their main concern was transmitting a health issue to their child (Figure 1A).
 - Prior to conception, more women with RA and AS consulted rheumatologists vs other HCPs; more women with PsA consulted general practitioners (GPs) and rheumatologists; more women with PsO consulted dermatologists (Table 1).
 - Whilst HCPs were proactive in bringing up the subject of pregnancy 42% of the time, patients took the initiative 40% of the time (patient's partner: 13%).
 - 47% had a treatment plan with their treating physician. Compared with patients with RA or AS, patients with PsA/PsO more frequently had their treatment plan discussed between their treating physician and obstetrician/gynaecologist (OB/GYN, PsA=56%; PsO=56%; RA=35%; AS=30%; Overall=42%).
 - Only 32% felt they received all the information they needed from their HCP on disease activity/treatment options in pregnancy. 41% of women on methotrexate prior to pregnancy were unclear of its safety in pregnancy.
- During Pregnancy**
 - During pregnancy, more women with RA and PsA consulted OB/GYNs vs other HCPs; more women with PsO consulted GPs and dermatologists; more women with AS consulted GPs (Table 1).
 - Upon discovering that they were pregnant, the main fear amongst women was passing on a health issue to their child (Figure 1B).
 - 37% of women stopped treatment due to a lack of information regarding its compatibility with pregnancy (Figure 2); 48% of women stopped anti-TNF treatment due to the same reason.
- After Pregnancy**
 - 41% of women felt they had to make a choice between treatment and breastfeeding.
 - 61% of women did not breastfeed; the main reason (45%) was that they needed to start treatment for their illness immediately and could not breastfeed while on treatment.

References

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Author Contributions

Substantial contributions to study conception/design, or acquisition/analysis/interpretation of data: CB, KP, AL; Drafting of the publication, or revising it critically for important intellectual content: CB, KP, AL; Final approval of the publication: CB, KP, AL.

Author Disclosures

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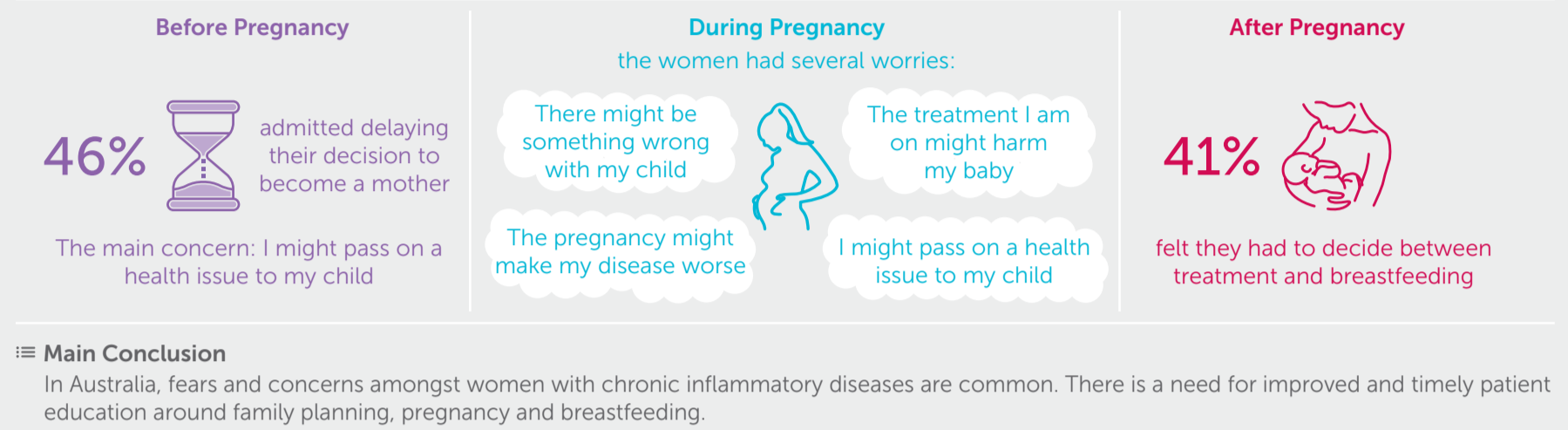
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SUMMARY

Question

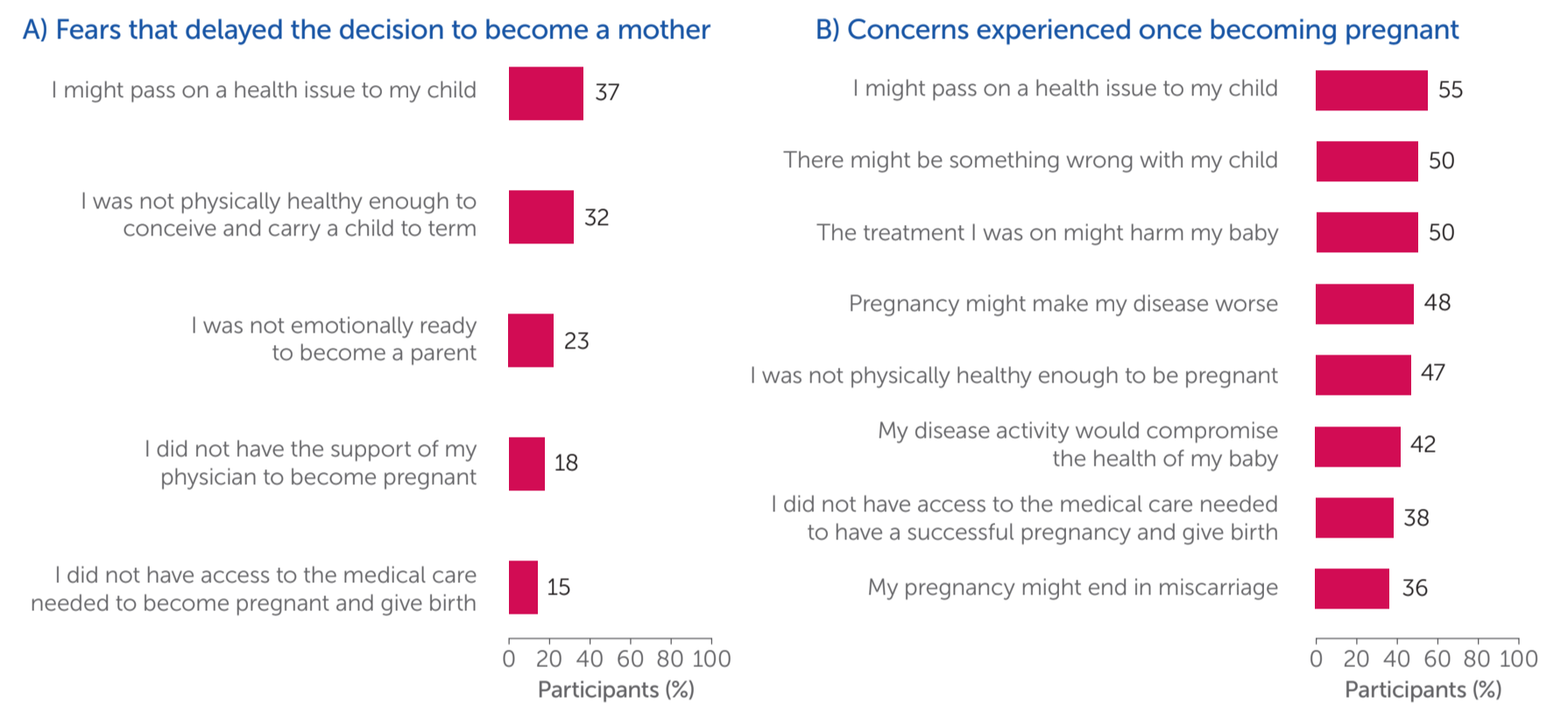
Do women with chronic inflammatory diseases in Australia feel appropriately supported when making decisions around disease management and pregnancy? What are their fears and what can be done to address these fears?



Main Conclusion

In Australia, fears and concerns amongst women with chronic inflammatory diseases are common. There is a need for improved and timely patient education around family planning, pregnancy and breastfeeding.

Figure 1. Fears and concerns of women with chronic inflammatory diseases around pregnancy



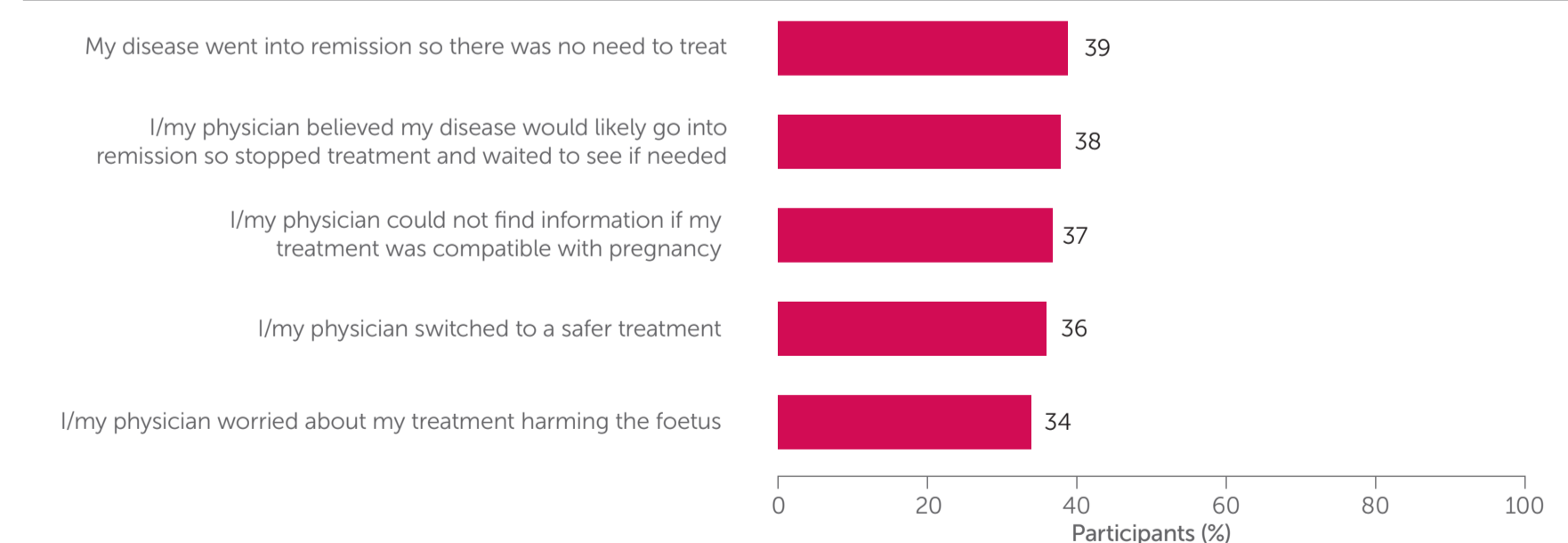
(A) Multiple answers were possible. The respondents were those who had concerns that delayed their decision to become a mother (n=62). (B) Multiple answers were possible (n=135).

Table 1. Healthcare professionals consulted by women with chronic inflammatory diseases before and during pregnancy

	Before Pregnancy					During Pregnancy				
	Rheum	Derm	GP	OB/GYN	Midwife	Rheum	Derm	GP	OB/GYN	Midwife
Overall (n=135)	39%	12%	31%	21%	14%	33%	15%	48%	47%	39%
RA (n=51)	57%	0%	33%	24%	14%	43%	0%	51%	59%	41%
PsA (n=27)	48%	33%	52%	19%	11%	44%	33%	44%	56%	41%
PsO (n=27)	0%	26%	11%	15%	19%	0%	41%	37%	19%	30%
AS (n=30)	37%	0%	27%	27%	13%	33%	0%	57%	43%	40%

Cells with orange text reflect most frequently consulted HCP for each indication. Multiple answers were possible (n=135). AS: ankylosing spondylitis; derm: dermatologist; GP: general practitioner; OB/GYN: obstetrician/gynaecologist; PsA: psoriatic arthritis; PsO: psoriasis; RA: rheumatoid arthritis; rheum: rheumatologist.

Figure 2. Reasons women with chronic inflammatory diseases stopped treatment during pregnancy



Multiple answers were possible. The respondents had stopped any of the following treatments: nonsteroidal anti-inflammatory drugs, immunosuppressants, topical products, non-biologic disease modifying antirheumatic drugs excluding methotrexate, non-biologic disease modifying antirheumatic drugs, methotrexate, steroids, anti-tumour necrosis factor, other biologics and orals (n=135).

CONCLUSIONS

- In Australia, fears and misconceptions are common amongst women with CID, often leading them to make difficult decisions around disease management and pregnancy.
- Patients should be informed about the risk vs benefit of well-controlled disease during pregnancy while continuing pregnancy compatible treatment, compared with cessation and uncontrolled disease.
- There is a need for improved and timely patient education and alignment within the HCP team to enhance patient confidence in decisions around disease management and pregnancy.