

# A Comprehensive Survey Assessing the Family Planning Needs of Women with Psoriasis

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## OBJECTIVE

- To evaluate the experience, concerns and family planning needs of women of childbearing potential with psoriasis.

## BACKGROUND

- Psoriasis (PSO) is an immune-mediated inflammatory disease, affecting around 3% of adults in the United States<sup>1,2</sup> and 2–6% in Europe.<sup>3</sup>
- The onset, diagnosis and treatment of PSO in women often overlaps with their peak reproductive years.<sup>4</sup>
- Family planning is challenging for patients in terms of balancing their own health with the health of their baby.
  - “...being pregnant completely flared up that would not be fun... But if I were to have a child, it would be my one shot. I couldn't see myself doing anything to hurt that one chance...” – **Patient with PSO, focus group conducted by the National Psoriasis Foundation (NPF)**
- Data on patients' family planning experiences are needed to optimize PSO management.

## METHODS

- We conducted a survey of women of childbearing potential to understand their experiences, concerns and unmet needs with regard to family planning.
- Eligible patients were aged 18–45, diagnosed with PSO (including patients with psoriatic arthritis).
- Patients were invited to complete a web-based survey on SurveyGizmo®, disseminated using e-blasts (the NPF, Advance E-News and TalkPsoriasis.org mailing lists) and social media (Facebook and Twitter).
- The survey included questions on patients' experience, concerns and educational needs, and were informed by the findings of focus groups and interviews of patients and their partners conducted by the NPF.
- Responses to the survey were collected Dec 2017–Feb 2018.

## RESULTS

### Patients

- 141 patients completed the survey: 65% were currently, or in the future would be, **trying to conceive**, 6% were **currently pregnant**, and 43% had **given birth in the last 5 years** (Table 1).

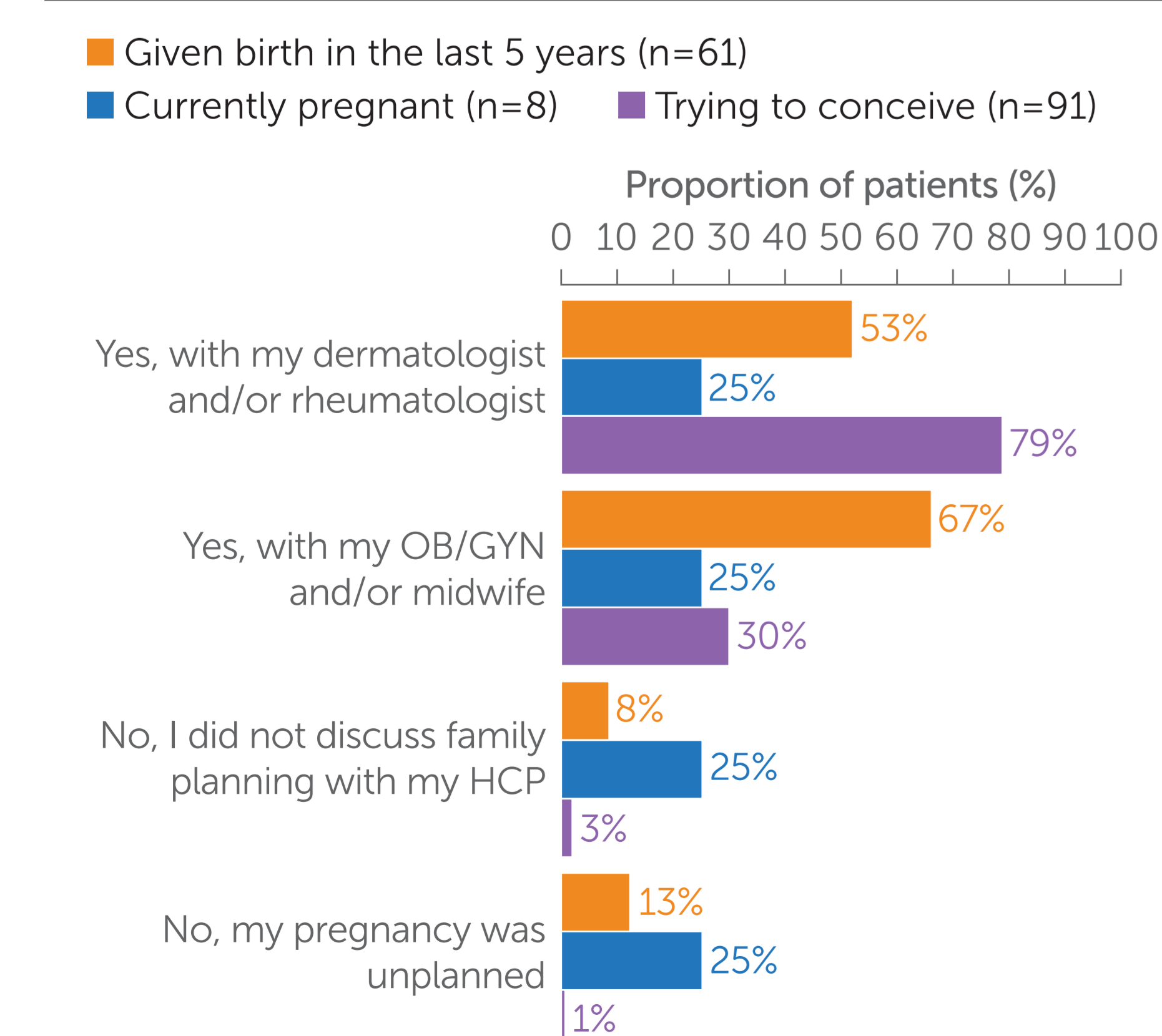
### Family Planning

- Figure 1 shows the proportion of patients who discussed family planning with their healthcare providers (HCPs).
- This family planning discussion was initiated by the PSO HCP in just 7.4% of cases (Figure 2).
- Many patients did not inform their HCP of their pregnancy right away, and many did not inform their HCP at all (Figure 3).
- Patients mostly used the internet, the NPF and their obstetrician/gynecologist or midwife for family planning information (Table 2).
- Flare management and the safety of medications during pregnancy were commonly identified by patients as unmet educational needs (Table 2).

### Treatment During and After Pregnancy

- Most patients stopped treatment for PSO during pregnancy (Figure 4).
- While many patients who stopped treatment experienced a worsening in the severity of their psoriatic disease (Figure 4), only 33% of those who had given birth in the last 5 years had a plan for what to do if they experienced a flare during pregnancy.

Figure 1. Did you discuss family planning with your HCP?



HCP: healthcare provider; OB/GYN: HCP from obstetrics and gynecology.

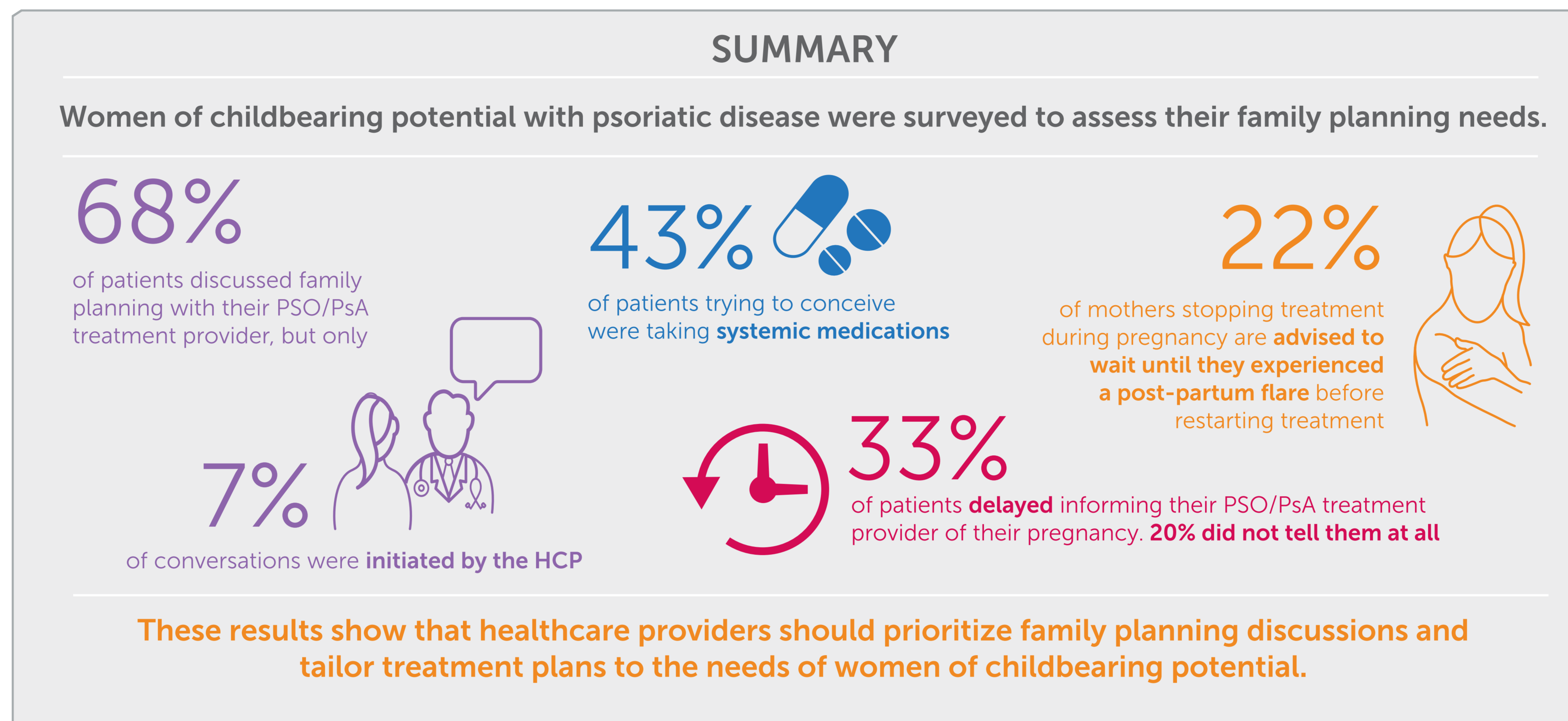


Figure 3. How long after you found out you were pregnant did you inform your PSO/PsA treatment provider?

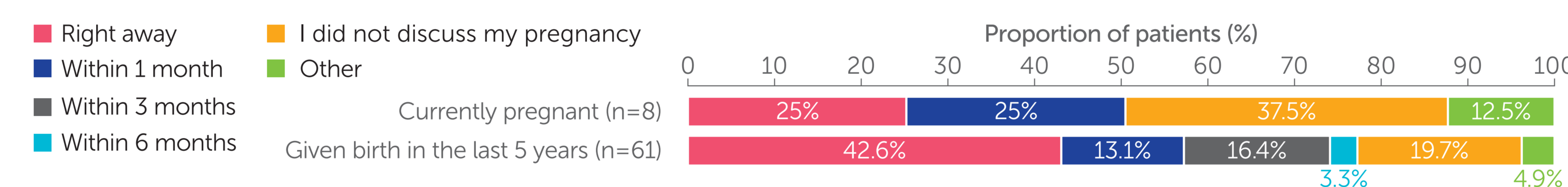
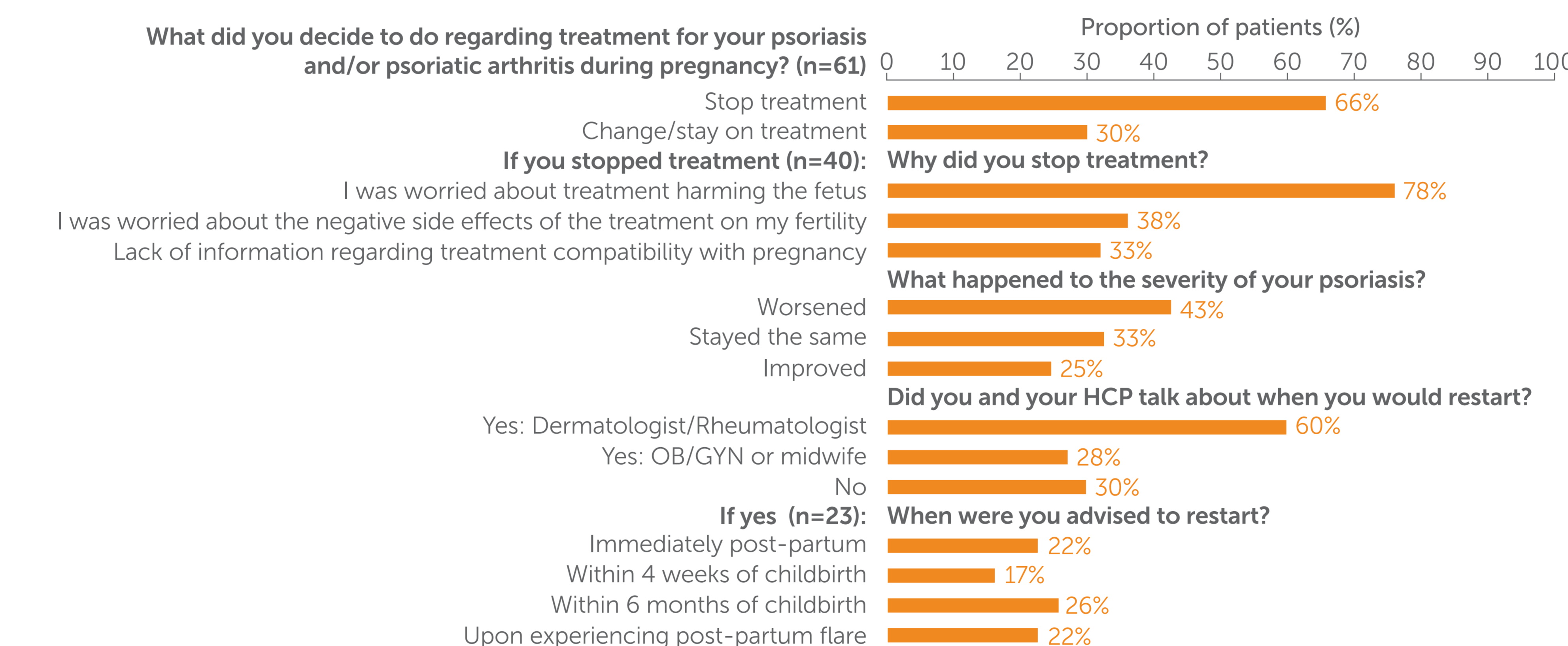


Figure 4. Stopping treatment for PSO/PsA while preparing for pregnancy for patients who had given birth in the last 5 years



HCP: healthcare provider; OB/GYN: HCP from obstetrics and gynecology; PsA: psoriatic arthritis; PSO: psoriasis.

Table 1. Disease and treatment characteristics

	Given birth in the last 5 years (n=61)	Currently pregnant (n=8)	Trying to conceive (n=91)
Age (years), mean	36	34	35
<b>Have you EVER been diagnosed by a HCP with PSO, PsA or both?, % respondents</b>			
PSO only	70.5	62.5	18.7
PSO and PsA	29.5	37.5	81.3
<b>Do you currently have..., % respondents</b>			
No or very little PSO	14.8	25.0	2.2
Only a few patches (1–2% BSA)	21.3	25.0	11.0
Scattered patches (3–4% BSA)	29.5	37.5	64.8
Scattered patches (5–10% BSA)	21.3	0	18.7
Extensive/very extensive (>10% BSA)	13.1	12.5	3.3
<b>Generally, what type of treatment are you on?, % respondents</b>			
Biologics	49.2	25.0	57.8
Phototherapy	9.8	12.5	48.2
Topical medications	42.6	50.0	47.0
Systemic medications	11.5	12.5	43.4
Over-the-counter products	34.4	37.5	22.9

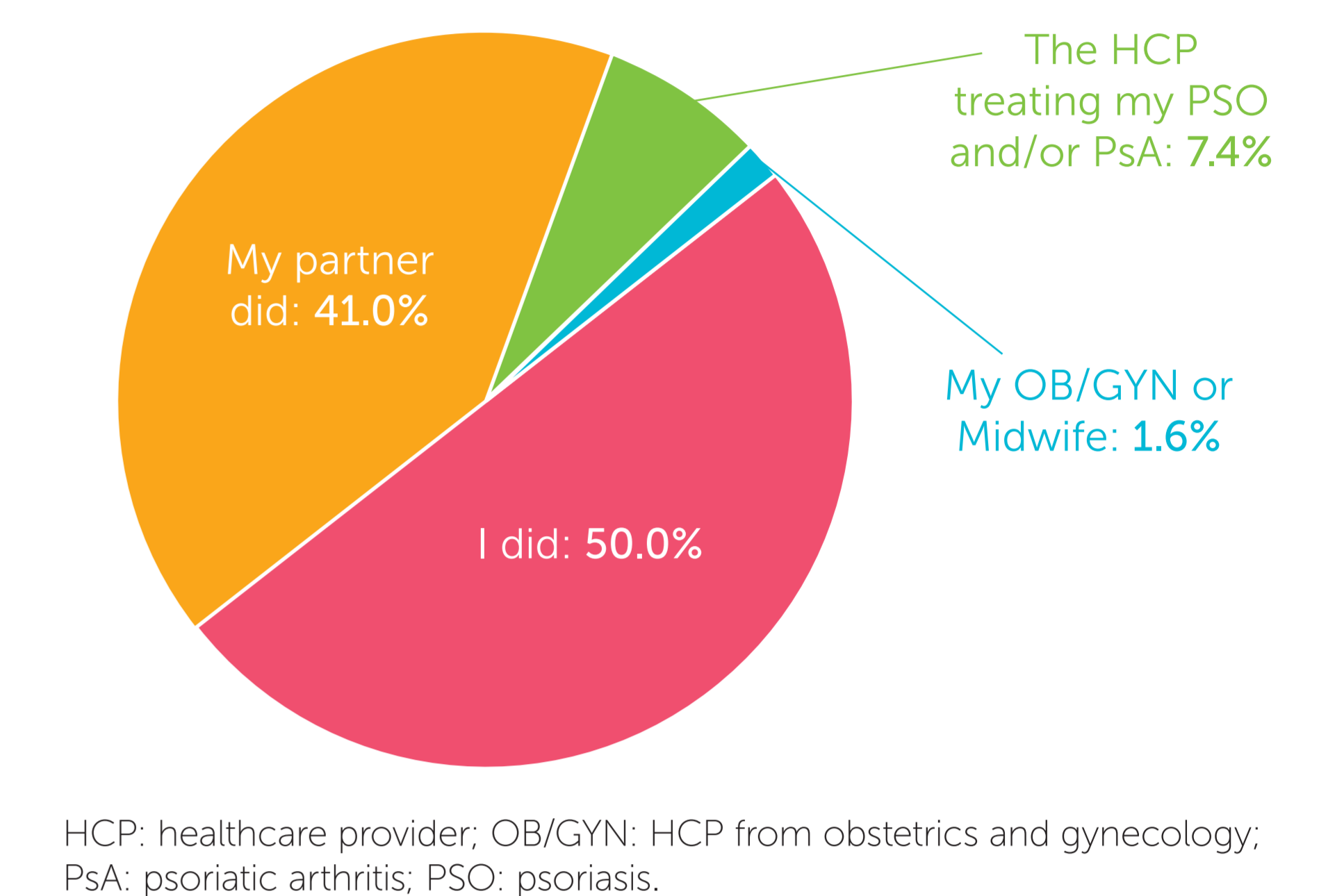
BSA: Body surface area affected by psoriasis; HCP: healthcare provider; PsA: psoriatic arthritis; PSO: psoriasis.

Table 2. Family planning information and resources used or desired by patients

	Given birth in the last 5 years (n=61)	Currently pregnant (n=8)	Trying to conceive (n=91)
<b>While preparing for pregnancy, where do you/did you get your information about family planning as it relates to your psoriasis and/or psoriatic arthritis?, % respondents</b>			
Online source (i.e. WebMD)	<b>45.9</b>	12.5	<b>80.2</b>
National Psoriasis Foundation	<b>42.6</b>	<b>50.0</b>	<b>78.0</b>
Internet forums/ chat rooms	34.4	<b>50.0</b>	<b>49.5</b>
OB/GYN or Midwife	36.1	<b>25.0</b>	52.7
HCP for psoriatic disease	<b>55.7</b>	<b>25.0</b>	28.6
Family and/or friends	6.6	<b>25.0</b>	37.4
<b>What type(s) of additional information do you/did you want related to family planning and psoriasis and/or psoriatic arthritis?, % respondents</b>			
How to manage a flare during pregnancy	<b>60.7</b>	<b>62.5</b>	<b>62.6</b>
Safety of medications during pregnancy	<b>77.0</b>	<b>50.0</b>	38.5
How the disease could affect the developing fetus	41.0	<b>62.5</b>	<b>64.8</b>
How disease is genetically passed/relative risk	<b>57.4</b>	25.0	<b>51.6</b>
<b>What other resources would be most helpful to you related to psoriatic disease and family planning?, % respondents</b>			
Internet resources that specifically address pregnancy and psoriatic disease	<b>71.7</b>	<b>62.5</b>	<b>47.2</b>
Lactation resources	<b>43.3</b>	<b>50.0</b>	<b>65.2</b>
Mental health resources	<b>38.3</b>	<b>37.5</b>	39.3
Patient support groups	35.0	<b>37.5</b>	<b>53.9</b>

The 3 most selected answers for each question by each subgroup are highlighted in bold. HCP: healthcare provider; OB/GYN: HCP from obstetrics and gynecology.

Figure 2. Who initiated the family planning conversation you had with your PSO treatment provider?



HCP: healthcare provider; OB/GYN: HCP from obstetrics and gynecology; PsA: psoriatic arthritis; PSO: psoriasis.

## CONCLUSIONS

- Many women of childbearing potential with psoriatic disease take systemic medications. However, many patients delayed or failed to inform their PSO/PsA HCP of their pregnancy, and family planning discussions were rarely initiated by the HCP.
- HCPs should prioritize discussing family planning, and plan treatment around/during pregnancy.
- The unmet educational needs of women of childbearing potential with PSO/PsA included the impact of treatment on their baby, and flare management during pregnancy.
- The relatively few respondents who were currently pregnant made capturing their experiences difficult.

**References:** 1. Rachakonda et al. J Am Acad Dermatol. 2014;70:512–6; 2. Kurd et al. J Am Acad Dermatol. 2009;60:218–24; 3. Danielsen et al. Br J Dermatol. 2013;168:1303–10; 4. Farber et al. Dermatologica. 1974;148:1–18.

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