

PREGNANCY LOSS RESEARCH GROUP

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BACKGROUND

- Gestational trophoblastic disease (GTD) is a rare pregnancy related disorder requiring expert care in GTD centres to ensure maximum cure rates.
- Molar pregnancy is the most common type of GTD with an incidence of 1:600 live births.
- It mostly affects women at the extremes of their reproductive age (<16 and >40 years).
- It results in a non-viable pregnancy and treatment involves uterine evacuation of the hydatidiform mole.
- Follow-up surveillance involves monitoring serum human chorionic gonadotrophin (hCG) until levels normalise.
- In 2017, the Irish National GTD Registry, Monitoring and Advisory Centre was established in Cork University Maternity Hospital

AIM

- To evaluate the experience of women enrolled on the National GTD registry over a 5-year period
- To establish a knowledge base for GTD in Ireland.
- To identify barriers and facilitators to weekly attendance at phlebotomy for hCG monitoring.
- To identify additional resource or service needs for Irish women with molar pregnancy.

METHODS

- A cross-sectional postal survey of women on the GTD registry was performed over a 5-year period (Nov 2020 to July 2021).
- The questionnaire designed by a multidisciplinary team contained 25 closed-ended questions and two open-ended questions to explore patient feedback.
- Data recorded anonymously was analysed using SPSS v28.0.
- Descriptive analysis was performed using counts and percentages. Valid percent was used to exclude missing data from calculations.
- Open-ended questions were reviewed for content analysis with responses categorised into groups.

National Survey of women on the Irish Gestational Trophoblastic Disease registry

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RESULTS

- 504 questionnaires were distributed with a response rate of 43%
- 23.6% of respondents (n=48) reported that other medical and healthcare professionals with whom they interacted throughout their treatment did not understand GTD.
- 49% of participants (n=106) rated availability of a rapid hCG result as their top priority and 34% (n=67) would opt for urine hCG monitoring if available.
- Categories which emerged in the open-ended questions included psychological support, bereavement counselling, peer support groups.



Figure 1: Replies to open-ended questions

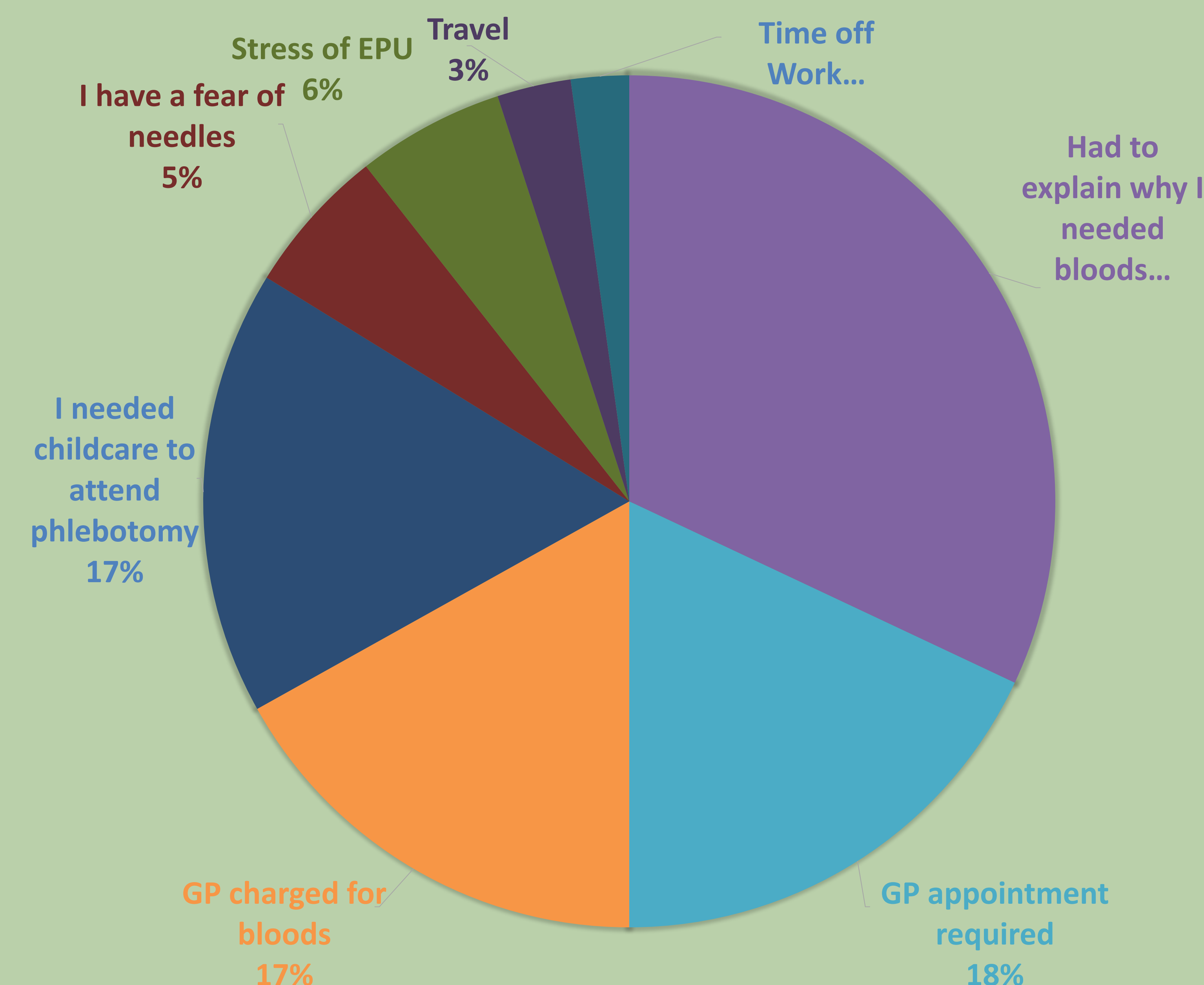


Figure 2: Factors impacting attendance for phlebotomy
GP = general practitioner; EPU = Early Pregnancy Clinic

KEY FINDINGS

- **A rapid hCG result was a top priority for women with GTD**
- **Attendance at the Early Pregnancy Clinic (EPC) for serum hCG monitoring was stressful for women following pregnancy loss.**
- **Further education and training on GTD is needed amongst Healthcare Professionals**

CONCLUSION

- There is a knowledge gap around GTD/molar pregnancy amongst Healthcare Professionals which should be addressed in medical and nursing curricula
- A separate phlebotomy service for women with molar pregnancy should exist outside maternity hospitals.
- Future service development should prioritise provision of psychological support and bereavement counselling for women with molar pregnancy.

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