



Genetic
Health
Services Victoria

THE ROYAL



WOMEN'S
HOSPITAL

Evaluation of a group for support after fetal diagnosis of an abnormality

SAFDA

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Outline

- Genetic counselling – what is it?
- Genetic counselling @ RWH
- Diagnosis of an abnormality
- About SAFDA
- The evaluation
- Outcomes

What is genetic counselling?

- Information
- Diagnosis
- Tests
- Counselling & support
- Education
- Research

RWH – Genetic Clinic

- Pregnancy referrals
- Previous baby / child with a birth defect
- Testing for adult onset disorders
- To arrange screening tests or diagnostic tests in pregnancy
- Counselling about results

Diagnosis of an abnormality

- Impact of “bad” news
- Choices
- Feelings
- Choosing TOP
- Bereavement care

Decision making

- Severity of the condition
- Understanding of the disorder
- Gestational age of pregnancy
- Family structure
- Cultural & religious factors
- Values & beliefs

Termination of Pregnancy

- The decision
- Preparation & admission
- Bereavement care

Aim of SAFDA

- In the beginning – 1994
- SAFDA 2001 – 2005
- Now

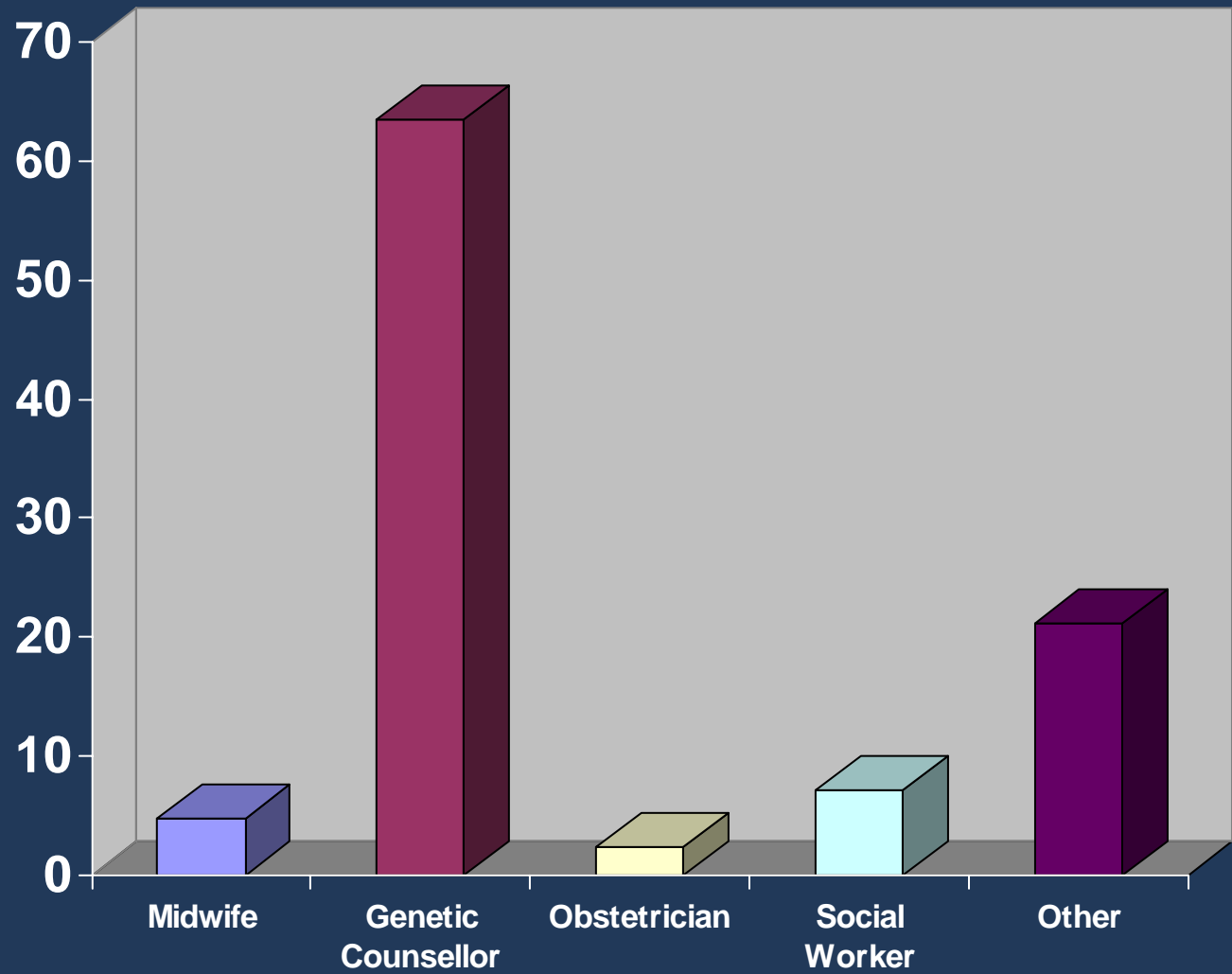
Method of Evaluating SAFDA

- Questionnaire – old
- Questionnaire – new
- Participants - 85

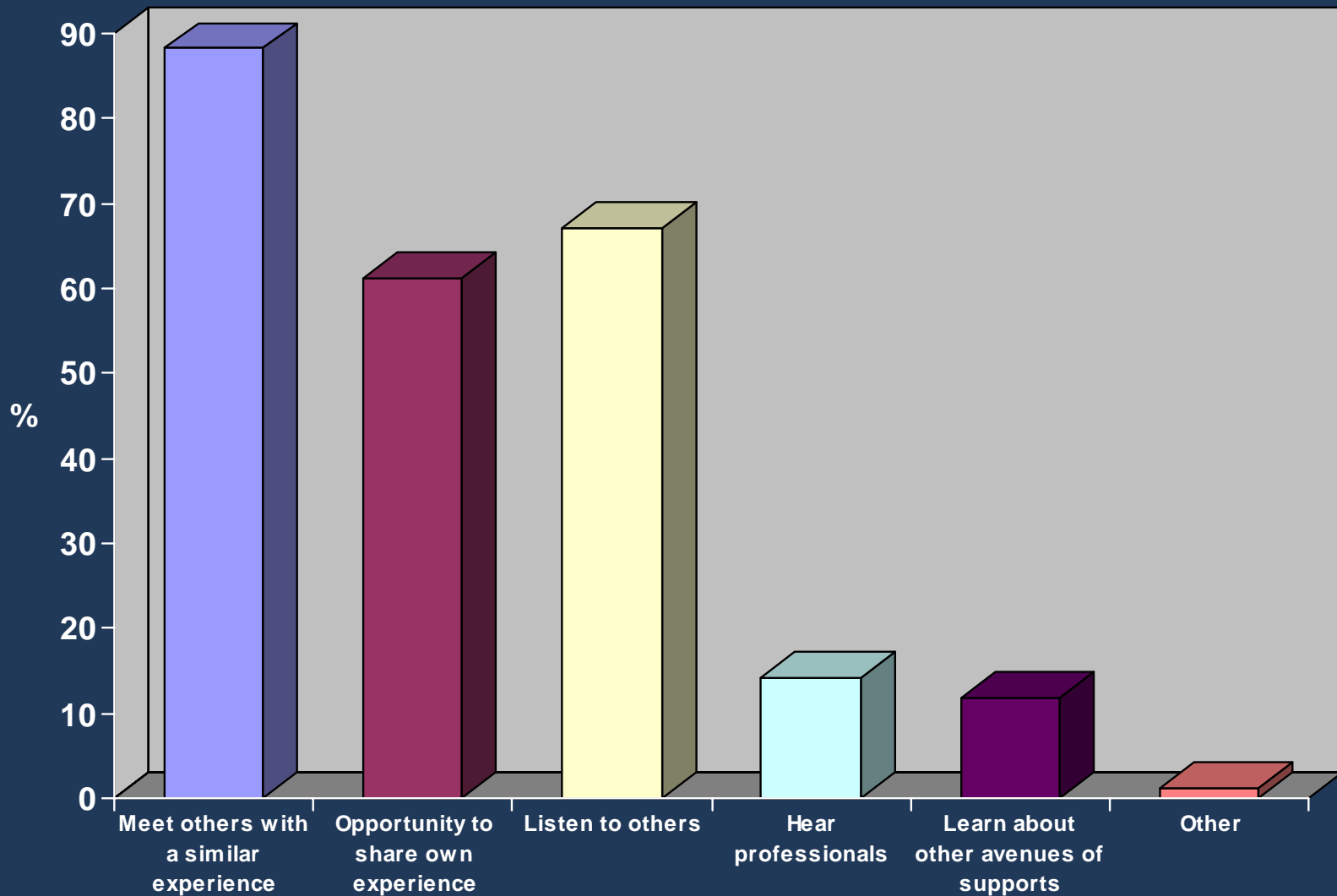
The Questionnaire - results

- Referral source
- Client expectations
- Helpfulness
- Format
- Size
- Venue
- General comments

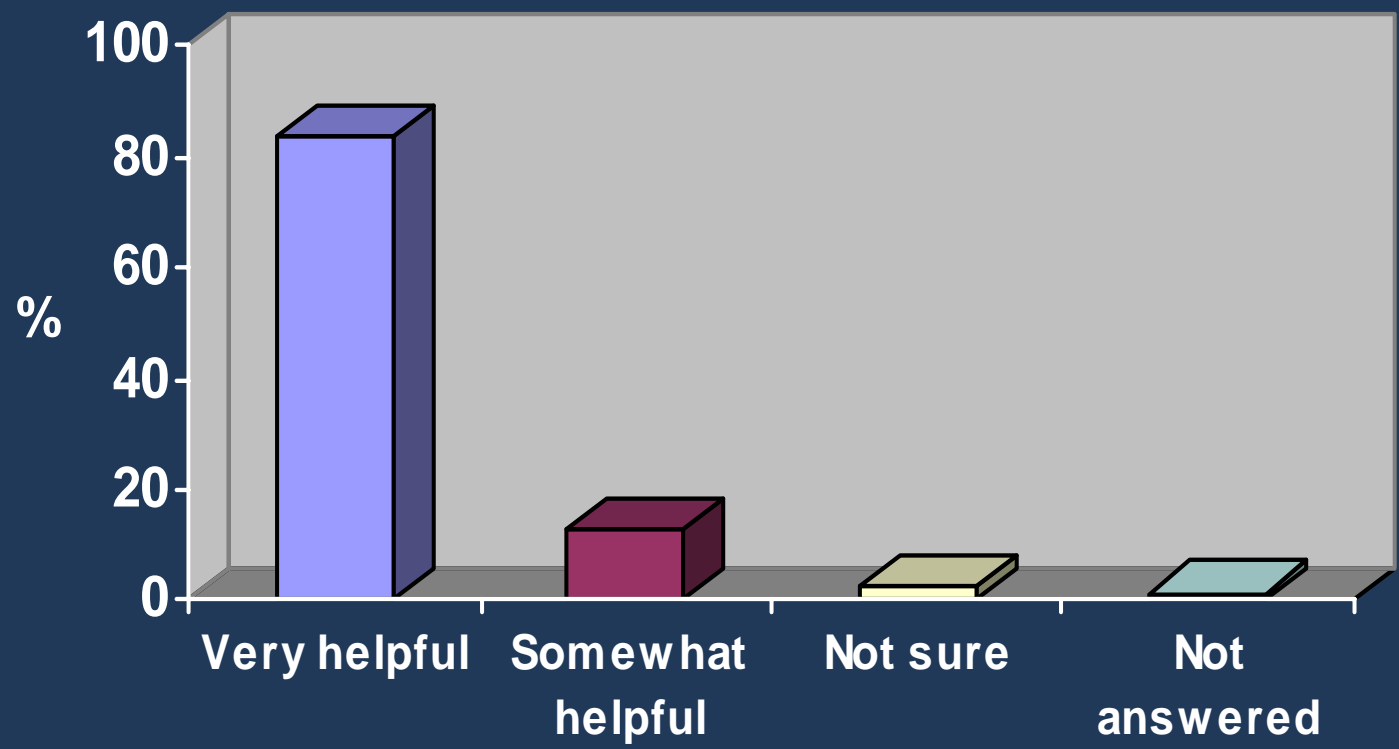
Referral Source



Expectations



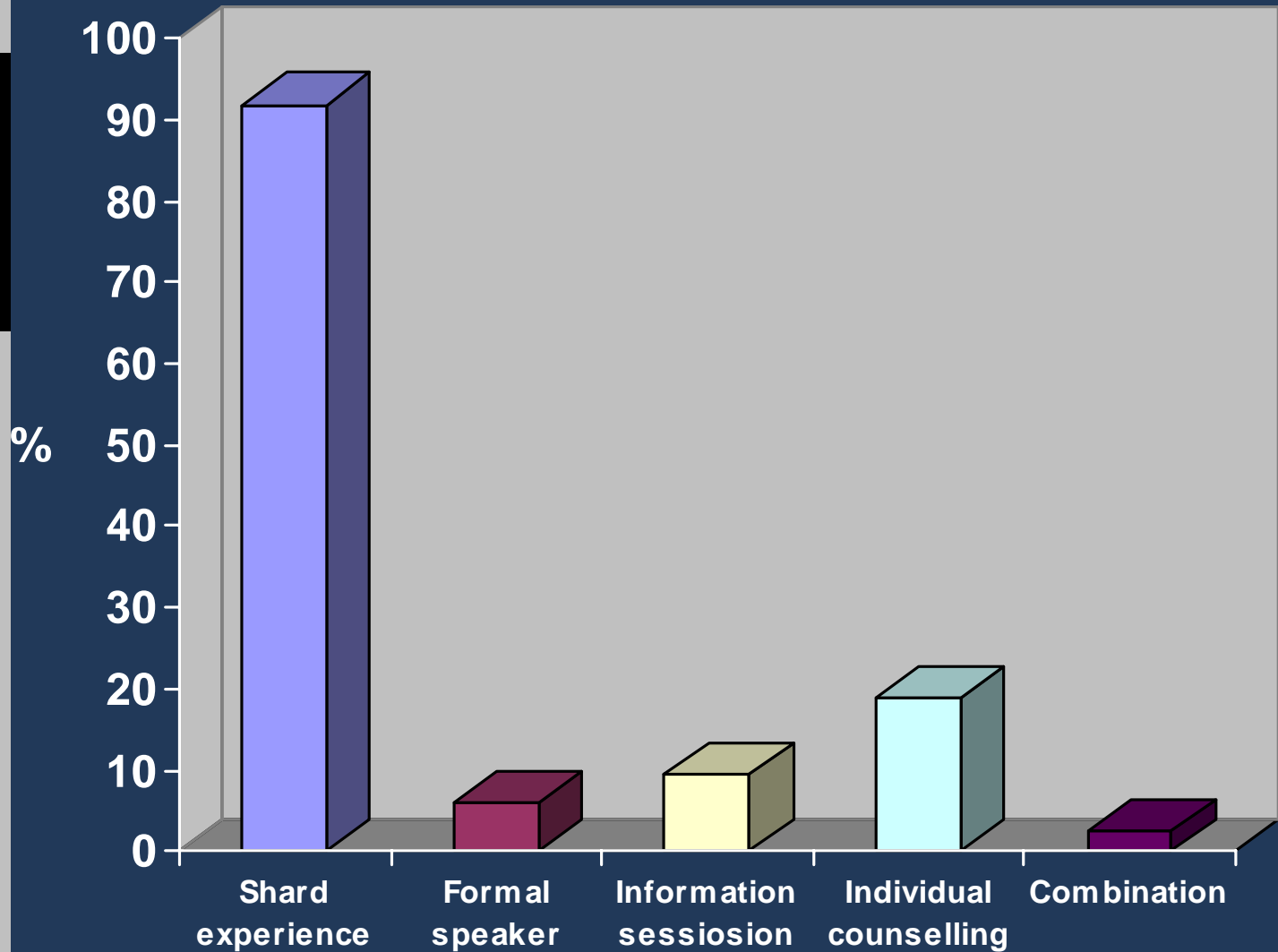
Helpfulness



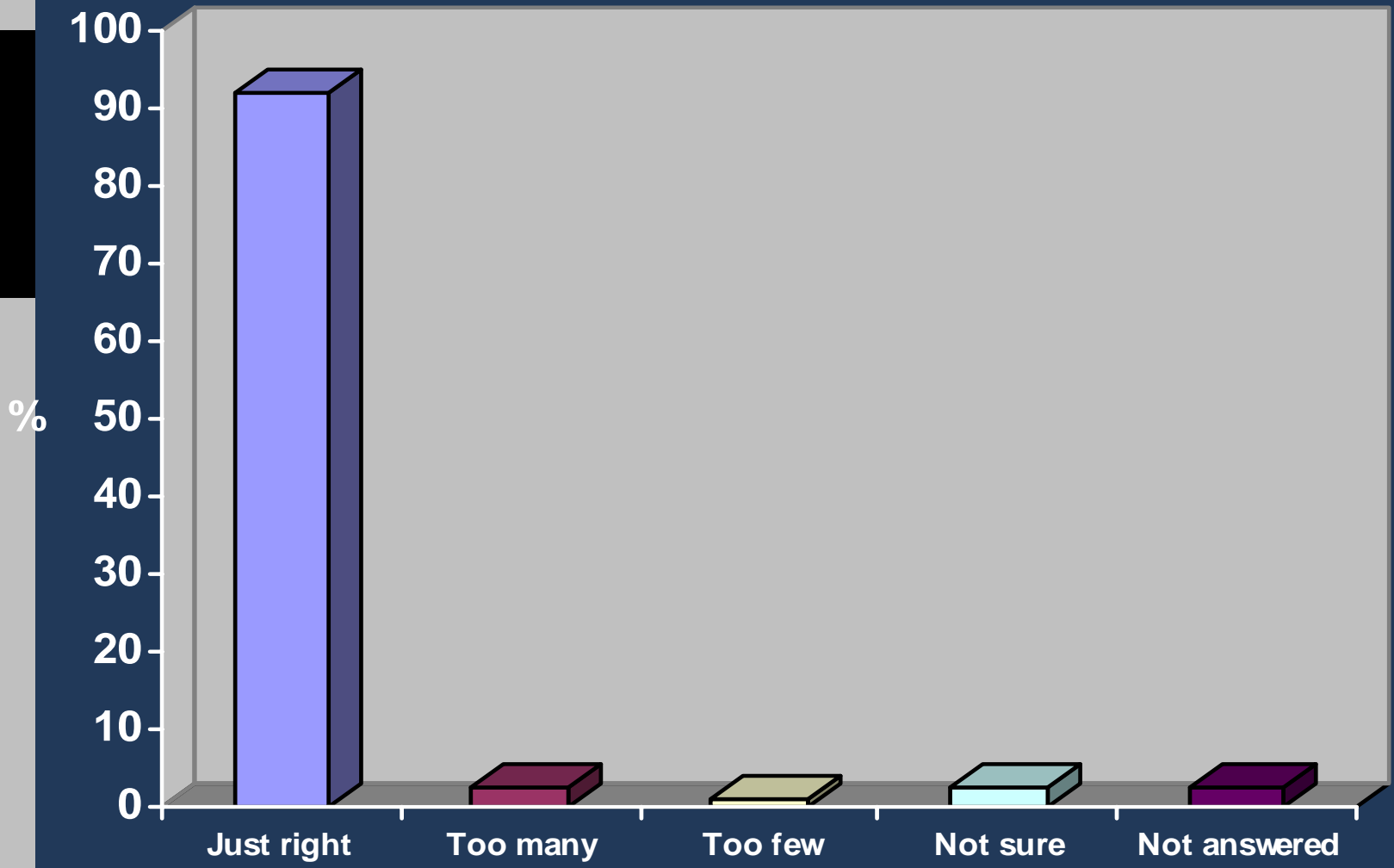
Comments on helpfulness

- *Allowed me to look at myself & realise I need to grieve*
- *Being a grandmother , very helpful*
- *Felt I'm not alone*
- *Getting to appreciate we are not alone - not "freaks". Also I rediscovered in my own heart where I am with my own grief*
- *Helped the healing process could relate to others & add comments or ask questions*
- *Helped to clarify own thoughts & emotions and express emotions that may have otherwise been suppressed*
- *Ongoing participation would be good only because sometimes "one off" is not enough*
- *Realized that there is other people who are feeling same as me*

Format



Size



General comments about being part of the group

- *Because each person was able to share their experience without feeling rushed*
- *Even though it was a small group I still felt I was able to understand and relate to the other persons discussions*
- *Good size, didn't feel pressured to contribute*
- *I feel 3 to 4 couples is a good number*
- *Probably optimum number, any more would change the dynamic gain.*
- *This size worked well but perhaps it was a unique group of very open people*
- *Wouldn't have wanted any more people*
- *A bit smaller may have been better but still very helpful*

Quote

- *“Very helpful” I felt that I had been dealing effectively with our loss. The SAFDA meeting however showed me that I still had a long way to go. I got a lot more from the session than I came here looking to gain. It was helpful to share our experiences & listen to others experiences very beneficial.*

Evaluation conclusion

- Positive forum
- Reduces feelings of isolation
- Safe empathic environment
- Opportunity to validate loss
- Illustrates important role of GC/SW
- Future studies

Limitations of the Group

- Small sample size
- Biased
- Recruitment limited
- Time and funding issues

Complex Grief

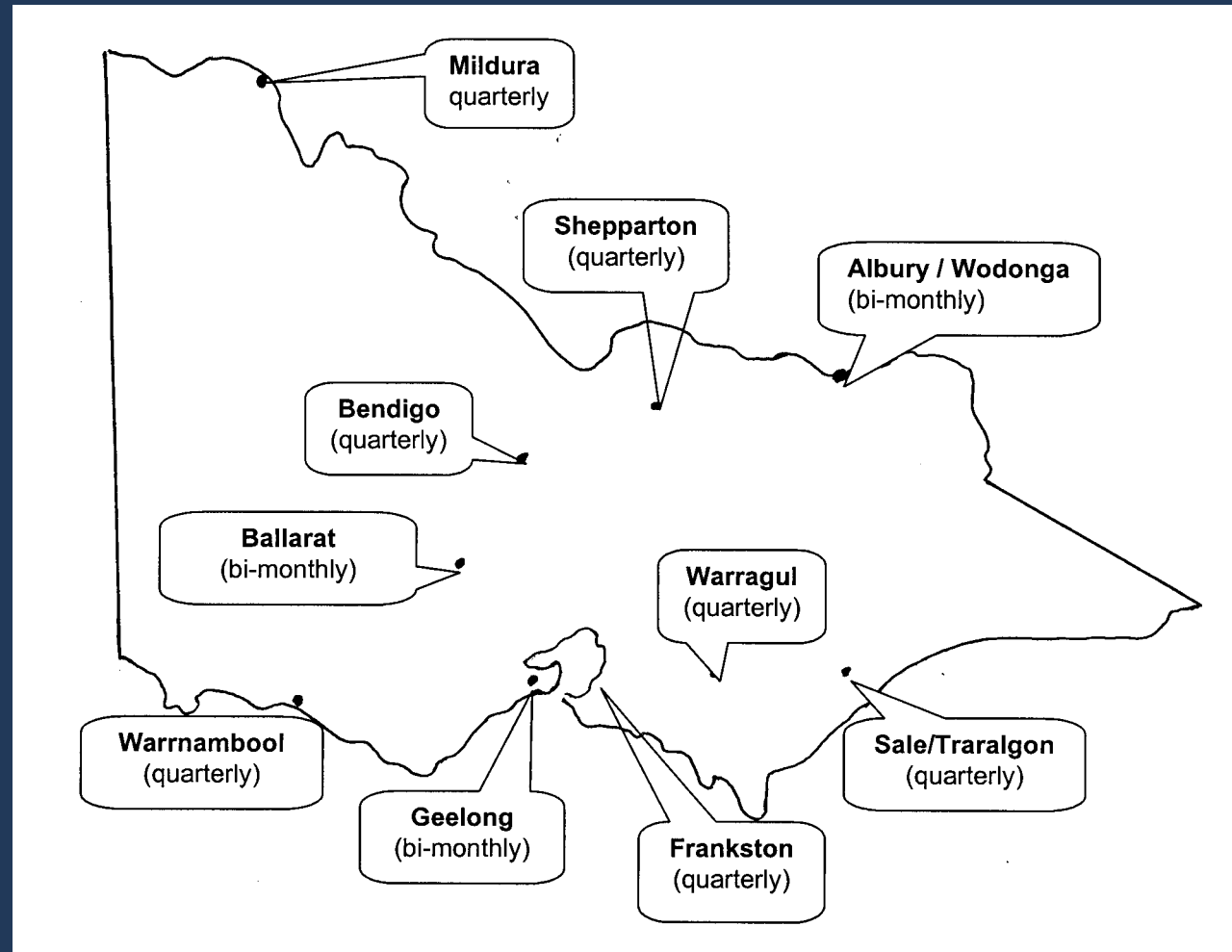
"Abortion can constitute a serious loss, (Raphael 1972) but abortion can take place without the knowledge of others, or even recognition that a loss has occurred."

DISENFRAANCHISED GRIEF –

Recognising Hidden Sorrow –

by Kenneth J Doka

Genetic Health Service Victoria - GHSV



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