

### Observations from postal research involving families of young people taking antipsychotic medication

Over the last 2 years, researchers and medical professionals from the University of Sydney and Northern Sydney Central Coast Area Health Service, Australia, have been involved in a naturalistic study monitoring the side-effects of risperidone in young people. Every 3 months over a 12-month period, the first author – the Research Assistant (RA) for the study – posted follow-up surveys to the young persons' parents, which were then completed and returned. The RA also maintained regular phone contact with the families involved. As researchers on this project, we believe that it will be of interest and potential relevance to journal readers for us to document some of the observations that were made regarding subject recruitment and administration of the study, because these observations may have wider applicability.

A total of 55 young persons were recruited into the study through doctors (paediatricians and child psychiatrists) working in the community. The young persons belonged to families that were predominantly from the Sydney metropolitan area. In all, 87% of these families came from areas of relative socio-economic advantage (1). The young people were taking low dose risperidone for a variety of non-psychotic illnesses.

Most of the young people and families considered suitable for the study were very willing to participate. The researchers considered that this uptake was encouraging, given that neither the participants nor their families received any direct therapeutic or financial benefit from being involved. Furthermore, families were prepared to make an ongoing commitment to the study despite having presumably higher levels of stress at home because of the illness of their child. Similar to the observations made by

O'Keefe and Berk (2) in relation to contact between patients and their clinicians, patients and families seemed to appreciate the regular written contact with researchers. The young people and their parents were generous with their time and willing to share their insights over the course of a year.

The RA posted 151 follow-up surveys to the 48 families that remained in the study after the initial baseline measurements were taken. He would typically send out the survey before the date it was due to be completed and would also phone the parents to remind them that this date was nearing. He recorded how long it took the family to return the survey. Follow-up surveys were returned on average 19.5 days after the date they were due to be completed ( $SD = 15.9$ ). In 22.5% of cases, the survey was returned more than 28 days after the due date. The RA attempted to make reminder phone calls to the family if the survey was not returned within 10 days of the date due. In 44.4% of cases, one or more (answered) phone calls were required before the survey was returned. (Note that these figures do not include instances where the survey was sent out late, returned early or not returned at all). In summary, considerable time and effort were required before all the surveys were returned.

Keeping in mind the demographics of this sample, families of young people taking an antipsychotic may be willing to participate in mental health research, and enthusiasm to be involved may remain even if the families do not receive direct benefit from the research. Parents in this study typically described the profound impact that their child's illness had had on their family and were more than willing to assist researchers. A regular comment was that parents 'never wanted another family to go through what they had been through'. At the same time, our experience is a reminder that a level of patience and persistence may be required by both

families and researchers if a study is being conducted 'indirectly' by post and phone. This consideration may be especially pertinent if a study requires repeated follow-ups over a period.

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### References

1. Australian Bureau of Statistics. An introduction to socio-economic indexes for areas (SEIFA), Cat. no. 2039.0 ABS. Canberra: Australian Bureau of Statistics, 2008.
2. O'KEEFE P, BERK M. Writing letters to patients. *Acta Neuropsychiatr* 2009;21:314–316.