

Consortium PSYCHIATRICUM

APPENDIX A. SUPPLEMENTARY DATA TO:

Heinz Katschnig, Peter Sint. Late 'Early Intervention in Psychosis':
A Family School for Learning How to Live with Schizophrenia.
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This appendix is a part of the original submission.
The appendix is posted as it was supplied by the authors.

Illustrative data for

Katschnig H, Sint P: Late “Early Intervention in Psychosis” – A Family School for Learning How to Live with Schizophrenia

Supplementary materials

While the school was not conceived as a research project and no data have been systematically collected for research purposes, some data are nevertheless available. A first data set represents the results of a three-year follow-up study involving interviews with parents and residents who had taken part in the first five courses (1986 to 1994). The second data set is more recent and reports the evaluation of the programme by parents at the end of the latest four courses (2015 to 2021). These are all observational data, from which no causal inferences can be derived. They illustrate the working method and the outcome of the courses at the school.

RESULTS OF A THREE-YEAR FOLLOW-UP STUDY ON THE FIRST FIVE CURRICULA (1986 TO 1994)

This study was carried out within the framework of a psychology master’s thesis¹ and a medical dissertation.² Altogether 63 families had taken part in the first five courses, 16 of whom had dropped out early and were replaced with families from the waiting list. Thus altogether 47 families had completed the course. Efforts to contact the families by post and phone were successful for 43 families who had completed the course and 13

families who had dropped out. Three patients in the completer group died (one by suicide) before the follow-up data collection. Information was available on whether the former residents had lived with their parents at the time of entering the school and three years after leaving it, as well as whether they had a day structure and finally on the number of days spent in a psychiatric inpatient unit in the three years before and after the course. These measures were contrasted between completers and dropouts (Supplement Table 1).

Supplement Table 1: Three-year follow-up study: the living situation, day structure and days in hospital of 56 residents of the first five courses between 1986 and 1994

	% Residents living with their parents		% Residents with a day structure		Days in psychiatric hospital before and after the course	
	At baseline	At follow-up	At baseline	At follow-up	3 years before	3 years after
43 Completers	79%	28%	14%	70%	252	66
13 Dropouts	70%	39%	15%	39%	214	96

Completers and dropouts improved in all measures, but completers much more so than dropouts. Considerably fewer ex-residents who had completed the course were still living with their families (28% vs. 79% at baseline) and

many more had a day structure at follow-up (70% vs. 14% at baseline). The number of days in hospital dropped to one quarter in completers if the three years before and after the school were compared.

Fifty-one parents answered a general question about their own well-being with 75% saying that it had substantially improved. Of the parents, 69% called themselves more optimistic than before and 88% said that their knowledge had improved a lot through the programme. Participation in the programme was an emotional burden for 57% of the parents and also a burden in terms of the time required. In Supplement

Table 2 residents are characterized by their parents according to five performance dimensions, and here substantial differences emerged between completers and dropouts in four of the five dimensions. Completers are judged as doing much better than dropouts in terms of carrying out meaningful activities, conversational skills, self-organization and skills for daily living.

Supplement Table 2: Three-year follow-up study: improvements of residents in five domains (completers vs. dropouts) as evaluated by parents

	Improvement of residents (% doing better) three years after leaving the school				
	Meaningful activities	Communication skills	Self-management	Emotional ties with parents	Skills for daily life
41 Completers	56%	51%	63%	61%	66%
10 Dropouts	20%	30%	30%	60%	40%

Finally, 41 ex-residents answered a questionnaire asking them to evaluate the programme of the school in retrospect. The majority (90%) said they would recommend the programme to other families and 72%

said that the one-and-a-half-year duration was fine. Furthermore, 97% approved of the inclusion of students (in addition to parents) for night shifts.

PARENTS' EVALUATION OF THE FOUR MOST RECENT COURSES (2015 TO 2021)

At the end of each course parents are routinely asked to anonymously fill in a questionnaire on how they evaluated the programme. It contains five questions to be rated on a five-point scale and offers the possibility to include comments.

a) Quantitative evaluation

For all these questions satisfaction ratings were very high. "Much" and "very much" together accounted for more than 84% in four of the five questions. Appropriately managing "intimacy at a distance" was still high (72%), but less so than the other items.

Supplement Table 3: Parents' answers (self-ratings) to five questions on the four most recent courses (2015-2021; N = 51)

	% Not at all	% A little	% Somewhat	% Much	% Very much
1. Has your knowledge on schizophrenia increased?		2	14	35	49
2. How helpful was networking and sharing experiences with other families?		2	14	37	47
3. Do you feel relieved by appropriately managing "intimacy at a distance"?	2	2	24	31	41
4. Has communication with your daughter/son improved?		2	12	51	35
5. How helpful was it having an assigned personal staff member as a coach?		4	8	27	61

b) Qualitative evaluation

I have learned a great deal; thank God I didn't miss a single parents' evening. It was also very good for my mind and well-being.

Thank you for the unconditional acceptance of my son and the professional support !!!!

I've learned that I'm not responsible for everything, that my son can take care of himself and needs support from time to time.

In retrospect, you all have made my son an independent, self-confident and partly even often happy person. For me it was very helpful + instructive. I have never dealt with this disease so intensively before and learned a lot! Thanks.

The parents' group could be reduced a bit - and/or - also take place in a different location :-)

An admirable, strong team with a focus on the well-being of the residents and their relatives! Thank you for everything!

In general, I consider the Pension Bettina to be extremely beneficial, so that those affected can return to a "normal" life.

I am very grateful for the time in Pension Bettina. We have learned a lot as a whole family and there is again a positive time today for all of us and achievable goals in the future.

Thank you for spending time together at Pension Bettina. The discussions were very supportive, and the work with family members and the group was good for me. It's a shame it's over.

Despite the corona pandemic, attempts were made to carry out the concept as well as possible. Thank you very much for the flexibility and the so important structure for everyone in these challenging times.

Your support was very helpful, but unfortunately, we had a bad time in our life, but it still helped us a lot. Thank you for everything.

My husband and I thank you very much, so we had the opportunity to meet really nice staff. It was a positive relief for me, but at the same time a lot of strain because of all the duties for Pension Bettina and at the same time being employed.

More physical exercise for the residents would be good.

I am infinitely grateful for the comprehensive help, the great understanding and the huge support that I was able to experience from the team at Pension Bettina!

I would not have thought that such a network (relatives, staff, affected persons) would work so well and that everyone would develop positively in the long term. A lot of positive experiences. Thank you for everything! Thank you that there is such a facility with such positive and solution-oriented staff. Thanks!

Parents' evenings could also take place every other week over the long period without losing quality :-)

The conversations with the staff are very helpful, you feel understood and accepted. It often took the tension out of a situation.

References

1. Mory C. *Schizophrenie und Lebensqualität. Nachuntersuchung der Teilnehmer des familienorientierten Wohnheims Pension Bettina.* Psychology Master Thesis. Faculty of Basic and Integrative Sciences, University of Vienna; 1997.
2. Mayr-Mauhart M. *Die Langzeiteffekte der Teilnahme an einem familienorientierten Wohnheimprojekt für Familien mit einem an Schizophrenie erkrankten Mitglied.* Medical Dissertation. Faculty of Medicine, University of Vienna; 2005.