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Introduction

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Why Are Family Interventions Important? A Family Member Perspective

Martin Gregory

Introduction

I have written this chapter as the father of a son who has suffered from schizophrenia. Our family unit benefited very considerably from participating in behavioural family therapy (BFT), and I will describe our experiences since our son first developed difficulties. After painting the picture of the family background, I will describe our family's story under the following headings:

- The roller coaster that comes about from mental health problems.
- Getting started on family therapy.
- The process and its structure.
- How the family benefited.
- Family meetings.
- How family therapy has helped with our son's social rehabilitation.
- The longer term outcomes of the family intervention.

The chapter includes a section written by my wife, who talks about how she felt during the family therapy sessions and the pressures it put on her emotions.

There is a section on the perspectives of our son, and the thoughts of the two key therapists involved are also given.

The chapter concludes with some final messages and my reflections on the whole experience.

A Casebook of Family Interventions for Psychosis $\,$ Edited by Fiona Lobban and Christine Barrowclough @ 2009 John Wiley & Sons, Ltd $\,$

The Background to the Family

This story and its messages relate to a family from England and to the developments within the family during the 1990s. I worked in a managerial capacity within the corporate world of industry and my wife worked in a sales development and logistics capacity within a Swiss owned engineering business. In the early 1990s, our daughter was proceeding through secondary and further education whilst our son (who was 5 years younger) was at secondary school.

Simon was a nice boy. He was well presented and well balanced and seemed to be taking life and education in his stride. Although never strong academically, he coped well enough and, like many boys, seemed to have a fairly laid-back approach. It was in sport that he really excelled and represented his school at rugby, cricket and badminton (the county too in this sport). Outside of school he soon became a very competent squash player and played for both club and county. However, it was on the hockey field that he really shone and from an early age his blond hair and skilful play ensured that he stood out when playing for school and county. He played for the County U14 team when only 12 and went on to get to the final stage of an England trial. It was a significant disappointment to all in the family when he failed to gain selection for the County U16 squad, but by this time he was beginning to get established in senior club hockey.

In addition to all this he was in the choir of a prominent local church, and with other typical boy's activities such as cubs and scouts, he had a busy and active life. With his laid-back and cheerful approach, it was always difficult to gauge what his potential in life really was, or if he was capable of achieving more in any of these activities or in education.

His life seemed to be evolving quite straightforwardly, and with his 6 GCSEs he went off at 16 to a local college to do a BTEC course with a view to going on to further education like his sister. Typically, he did just enough to be accepted on a degree course in Transport and Logistics, this being a course of his own choice, although his grades were such that he had only two colleges to choose from.

So in September 1993, Simon went off to Wales to start his degree course with us as his parents having no hint of any problems or difficulties in his life. Being at college as opposed to a university, no student accommodation was available and so he found a bedsit in 'downtown' Swansea and seemed to settle in quite quickly. On the hockey front, he quickly established a regular

first team place with the local HC, one of the top two sides in Wales, and was selected for the Welsh Universities squad.

It was only in his second term that there was any hint of a problem and it was during this period that we discovered that he was a regular user of cannabis (subsequently it was established that he had started taking cannabis several years earlier). It transpired that he was not attending college courses and spent much of his time shut in his own room. Then the phone calls home started late at night and during the night with the regular use of expletives (not previously a feature of his dialogue) and with him shouting and yelling accusations at both of us and indeed all and sundry who had any involvement in his life. Appointments were made for him to either go to a doctor or for a doctor to go to him, but neither came to fruition. The extent of the problem became clearer when eventually I was able get access to the bedsit and was told by Simon that he had just seen on TV that he was to become the next King of England.

It proved extremely difficult for us to ascertain what to do next because while it was possible to get very general information from libraries and the family GP (general practitioner), nobody actually offered advice on what to do. This was brought to a head when the landlord of the bedsit wanted Simon evicted due to a potential threat of violence to others living in the house.

We did not know where to go for real help: people such as our GP showed sympathy but were unable to offer practical advice on what actions we should take. Eventually I spoke to my MD at work, who had some experience of mental health services and he arranged for us to meet the Manager of a local Day Centre who explained to us that we were entitled to request a mental health assessment. With this new information we were able to access a social worker who was the first person to offer practical help. In due course, he facilitated an assessment with police in attendance involving a really helpful psychiatrist and a GP, as well as the social worker himself. Thanks to the great skills of the psychiatrist, Simon was admitted to the psychiatric unit in Swansea as a voluntary patient.

The Roller Coaster

In April 1994 Simon started his first period of hospitalisation in Wales, but immediately ceased to recognise us as his parents and blamed us for his problems. Communication with him became virtually impossible and although we travelled down each weekend to see him, he would never talk

to us. Whilst we were given an indication that he may be suffering from schizophrenia, at no stage was this confirmed and neither was he informed of this. After a few months he was transferred to supported accommodation locally, and at this stage he became slightly more communicative and was showing signs of recovery. This progress continued and after a few more months he transferred back to his home locality and returned to live in the family home.

Everything seemed to be moving forward for him; he resumed college, he got a job relevant to his career ambitions, and his hockey went well – indeed he represented the county at senior level. But then the roller coaster started, which was probably attributable to his own denial of the illness. He stopped taking his medication and returned to cannabis for comfort.

The next few years were a nightmare for all of us with difficult periods living at home, attempts to live in his own accommodation which highlighted his own fears, and several periods of hospitalisation. He blamed us for his problems, would not communicate with us rationally, and yet it was still us he turned to when in difficulty. He could not live with us but he could not live without us.

During this period, support from the community health team was spasmodic and ineffective and the fact that Simon kept disappearing and was non-compliant contributed significantly to this. Eventually, yet another major crisis arose whilst he was living at home, but this time his behaviour led to him being sectioned, which was the first time that his problems could be addressed on a compulsory basis. The behavioural circumstances leading to this included Simon locking himself in his room and seldom coming out. When he did come out, he was threatening and aggressive, particularly to his mother. In addition, a neighbour complained that Simon was trespassing on their property and spending time in a shed they had in an adjacent field. The social worker (supported by the psychiatrist) considered that sectioning was the only way forward. A change in personnel also facilitated a different type of approach to his care and treatment, and also to the way in which we were treated and involved as his carers.

Getting Started on Family Therapy

The new community psychiatric nurse (CPN) had recently completed a BFT training course, following the model originally developed by Falloon,

Boyd and McGill (1984) and the social worker was also due to attend the same course. As a result, they suggested one day, when Simon was slightly improved, that perhaps BFT might be helpful to us as a family. They were keen to try their new intervention and considered that our family might benefit from BFT, particularly due to the communication problems we experienced. In their work with us, the approach they used was described in a detailed manual (Falloon *et al.*, 2004).

As his carers, we had received very little support and were still ignorant about the illness and its treatments, and so when we were offered help as a family, we saw this as a potential lifeline – what could we lose? Could this programme really help us to understand things better and would we have an opportunity to talk through some of the problems that we as his carers faced? Although we were by no means certain of the answers to these questions, it did seem that the model of family work that was offered to us (BFT) could not make things worse so we accepted the offer.

We were given an outline of what BFT consisted of and what the potential outcomes and benefits might be, but we really needed very little persuasion. The therapists felt that it would be a good idea for our family and that it was possible that BFT would give us some of the information and support that we were looking for. In particular, we were told that the communications aspects of BFT might help the day-to-day relationship within the family. It was explained that we would need to meet every 2–3 weeks or so for maybe an hour at a time, and that there would be some practical work to help improve our skills.

Simon's sister did not take part in the sessions. It was impractical for her as by now she was living about an hour away from home and worked even further away. Apart from that, she had become a little nervous and reluctant to get too involved as Simon had seen her new home as a 'bolt hole', and when he had turned up there she became a little frightened. She was also building a new long-term relationship and was wary of this being disrupted. In any event, she came to the family home infrequently.

Getting Simon to buy in was a different matter. He was still in hospital at the time of the offer although he was allowed home on leave one evening a week. He was ambivalent about getting involved in the programme himself but, very fortunately, did not put any barriers in the way for his Mum and me to get started. Although this was not ideal within the BFT model, the support team now engaged with our family had the foresight to agree to proceed on the basis that Simon might join in later.

So after a preparatory meeting talking about goal setting, we started the programme with sessions being held in the family home on the evening of Simon's home leave. We left the lounge door open so that we were not talking behind closed doors, and for the first session or two Simon showed no interest in our discussions. However, it was not long before he started to pop in for a few minutes and gradually he became involved in discussions. This soon led to the agreement that home leave night was BFT night and this, linked to a Chinese take away (always a favourite of his!), made the whole package quite acceptable – indeed it became an evening that he looked forward to.

The Process and Its Structure

As with much of Simon's care in recent years, we have been very fortunate with the calibre of staff in his support team. This includes the psychiatrists, social workers, CPN, the members of assertive outreach and the support team for the supported house in which he now lives. This certainly applied with the therapists delivering BFT who were his social worker (who has been involved for many years) and his CPN. We will always be grateful for the way they handled our BFT programme, which was done sympathetically but in a very supportive way to each of us. The same two people remained with the programme for most of the modules so providing continuity, but importantly, this enabled them to gain a detailed understanding of the make-up of the family and the problems faced by each family member. It also was important to us that they were members of Simon's support team so that they did not walk away from the case at the end of each BFT session.

As previously explained, our BFT programme started without Simon, so immediately on commencement we were able to talk about ourselves, our attitudes, and address the objectives of the programme and the goals for mother and father individually. This was done by separate one-to-one meetings, and then sharing the goals of each of us and discussing these openly. For both of us, it was key that we found our own time and space both individually and together, and maybe have a holiday that we could enjoy without undue worry and stress. This in particular was something that we were able to revisit throughout the programme and see just how far we were moving on in achieving this.

It was very soon after this that Simon joined in the sessions, albeit initially for very short periods. At the beginning of each meeting, he would agree how long a period he thought he would be comfortable to stay, be it 10 or 15 minutes, and as soon as that period was up he would leave. Much later he felt able to stay for longer periods extending to 30 and then 45 minutes.

Over many months we addressed each of the modules within the model including positive and negative communication, making requests, expressing feelings, active listening and sharing information. While clinicians would probably find it helpful to know how long we spent on each topic and over what time frame, as a family member I did not experience or think of the therapy in that way. Neither can I remember at this stage how long we spent on each topic.

We also spent some time learning more about the illness, positive and negative symptoms and most importantly the types of medication. This was the first occasion in Simon's illness that we had been given the opportunity to talk freely about these things and without feeling the pressure of a time factor (as applies in clinical appointments). If we did not have time to deal with a particular query, we always addressed it next time round.

The really practical outcomes that we talked and learned about were family meetings (which I will come back to later in the chapter) and problem solving. We did not realise when we did the problem-solving work just how often we would use this simple technique (or at least our version of it) in the future.

The session on early warning signs proved the most problematical due to Simon's vulnerability to so many of these signs. This particular session was very upsetting to him (and consequently to us) and we had to keep 'parking' it until eventually, when he was so much better, it was completed partly outside of the meetings, and indeed it then resulted in the agreement of an advance directive to give guidance to each of us on our actions should there be signs of a relapse. An advance directive or advance statement is a document which mental health service users can complete when they are well. It allows them to say how they would like to be cared for during times of mental health crisis, loss of capacity and/or admission to acute psychiatric care. It can cover medical care and treatment and domestic arrangements.

Most of the sessions took place in the lounge at the family home, but we were always mindful of who sat where and we tried to rotate the seating positions. This was particularly important in the early stages when it was not possible for Simon and his mother to sit opposite each other. This

was linked with one of Simon's ideas that his mother could control him through her eyes.

There was a period during BFT when it was inappropriate for Simon to leave hospital and so there were two occasions when the sessions took place in a room in the hospital. This worked quite well and it was also good that ward staff could see that it was possible for BFT to be handled within an acute care environment.

How We Have Benefited

This is arguably the easiest section in this chapter for me to write primarily because the benefits are there for us all to see and secondly because I talk very frequently about these benefits in a variety of forums as well as privately. In essence, BFT has helped all family members to get their life back and to cope with a variety of different situations and problems, and I list below some of the ways it has achieved this although it should be made clear that these are not listed in any significant order:

- It has enabled my wife and me to become fully involved in the care and recovery programme because we are better equipped to understand the part we can play and how to become involved.
- BFT has enabled us all to gain a greater understanding of mental illness and its treatments and increased our knowledge very significantly.
- The communications modules such as talking positively and negatively have improved our skills in being able to handle difficult situations, address issues and generally improve relationships within the family.
- It is the treatment that best uses the unique knowledge and experiences of each of us in the family so that we have all felt able to contribute to the process as equal members of the team.
- The fact that our sessions have been held regularly (with a date fixed for the next session on each occasion) meant that we were able to meet with knowledgeable and supportive professionals on a frequent basis. We all welcomed the opportunity for regular dialogue with, in our case, those who were key members of the support team.
- The fact that one or two sessions were conducted in an acute care setting helped considerably because it meant that when we visited him in hospital, the awkward and uncomfortable silences were replaced by

11

a purposeful and sometimes productive BFT session which gave a lot more meaning to a hospital visit.

- Hopefully, it can be seen that from all these benefits we were able to reduce stress levels significantly and develop coping mechanisms. When a problem loomed, we were able to say to ourselves, 'That's something we can discuss at our next BFT session.'
- In the early stages of the family intervention, the BFT sessions were the only occasions when Simon communicated with us so they became very valuable to us both emotionally and practically.

Maintaining Progress: The Family Meeting

As part of our help from the therapists, we discussed whether or not a regular family meeting would be helpful to us all. This would be a meeting that we could run as a family without either of the therapists being present. In the end, we concluded that it was worth a try and so on alternate Sundays (Simon came to the parental home most Sundays when well enough) we had a short family meeting in the kitchen at home. We found that in the early stages of these meetings the real benefit was sitting around a table and talking to each other albeit in a semi-structured way and for only 4–5 minutes at first, later increasing to 10–15 minutes and this was a major breakthrough.

The agenda concentrated on fairly practical things like any travel arrangements needed during the week ahead, homework for the next BFT session, possible sporting activities for Simon and other domestic or leisure matters – we tended to avoid topics that might have been difficult at least in the early stages. One of us would take a few notes whilst another would chair the meeting – Simon performed both these tasks at various times. Gradually, we settled into a routine for these meetings and found them really helpful in opening up a dialogue that might not otherwise have been possible.

By having family meetings before Sunday lunch, we were able to deal with many issues in the meeting leaving the lunch itself as 'protected' time. This avoided difficult dialogues over the lunch table so resulting in a much pleasanter family occasion. As our relationships began to improve, we found less need to have the meetings on such a regular basis and just brought them into play as and when a specific need arose, but the mechanism of the family meeting was always there for us to access when needed.

In more recent times, we have used the family meeting approach to facilitate discussions regarding activities relevant to Simon's social rehabilitation.

The Contribution of Family Therapy to Social Rehabilitation

I hope I have painted a picture which has reflected the very difficult times we all had in Simon's early years of experiencing mental health problems. At the time of writing, it is just so great to be able to say how well Simon is now doing and to reflect on the progress he has made that we would never have dreamed was possible several years ago.

We still meet regularly, albeit at Simon's request only around every 3 months, for a session called BFT (one therapist has remained throughout and the other is Simon's current key worker), but in truth these are more care programme reviews or, to be more specific, they are meetings at which we discuss Simon's social rehabilitation. However, we have continued to use the description BFT because it is a term that we are all comfortable with and we all use the meeting framework we have developed and the skills we have learned to move Simon's activities forward.

I really believe that this framework helps significantly in the planning and implementation of the social rehabilitation agenda for a whole raft of reasons which include the following:

- Each of us has been able to input his/her own perspectives into actions.
- We all feel involved in the care and recovery programme.
- Individual actions are discussed and agreed.
- We all share successes.
- Through these meetings we have been able to discuss freely and agree (sometimes using the problem-solving model) actions and outcomes such as
 - assessing suitable and realistic activities;
 - planning a short break/holiday;
 - addressing day-to-day issues;
 - reviewing achievements and agreeing targets.

As an example, the problem-solving model was very helpful when we planned a short break and we addressed this in a family meeting type setting.

Simon had not had a holiday for around 6 years, the last being when he had a major relapse in Corfu and spent several months in hospital there. As a result, there were lots of considerations in reaching our decision, not least the importance of being in a location that Simon would feel comfortable in. So we talked through the pros and cons of each of these destinations covering travel arrangements, where we would stay and the potential activities at each. Then Simon scored each out of 5, this being a simple technique that had been used before and in the end he chose Skegness probably because he knew it from when he was a child and he had a feeling that he would feel secure there. So the three of us duly went to Skegness and had a really good time there which proved to be a really big stepping stone in Simon's rehabilitation.

We have used this format on several occasions including reviewing potential leisure type activities and each time it has worked really well.

The Longer Term Outcomes of the Family Intervention

As I write this, Simon's progress has been such that we all have a comfortable and relatively stress-free life totally compatible with the objectives we set when we started BFT many years ago.

He still lives in excellent supported accommodation but the time is fast approaching when he will move into his own flat or house with outreach type support. He has a part-time job in a local garage which he thoroughly enjoys and which has been key to him feeling able to lead a normal life again. The people he works with are very helpful to him and he does not appear to encounter any stresses in this work environment. He plays hockey every Saturday in the winter months and is keen to progress his golf maybe by joining a local club. He has recently bought himself a car and this too has given him a big boost.

All this progress is attributable to several things not least of which are the efforts Simon has made himself to move his life forward. He has continued to receive great support and help from psychiatrists, assertive outreach staff and the visiting support team in his accommodation. However, there is no doubt in my mind that the BFT programme has also played a significant part in his treatment and development, particularly in the development of his interpersonal skills and levels of activity. BFT in this case has been a really good example of how psychological treatments can interface with

medications and an efficient care programme to give a holistic approach to his treatment with a very satisfactory outcome to date.

Within the family communication, discussion on any topic is now so much easier and more effective than hitherto, and whilst much of this is clearly to do with Simon's improvement, there is no doubt that the skills we all learned and often use have also enabled this to happen. We continue to use the problem-solving method, and recently used it to very good effect in helping Simon to deal with his anxiety about visiting the dentist to begin to have his teeth looked after.

Simon's relationship with his sister has improved quite substantially and they are probably as close now as they ever have been. He occasionally visits her on his own, which has never really happened before, and he is absolutely devoted to her two little boys, his nephews. He is really proud of the family unit and gives it very high priority at all times.

For my own part, since retiring, I have become an active and involved carer with a part-time role in promoting and facilitating carer involvement and a full portfolio of speaking and training engagements on a variety of mental health topics, and I feel that I contribute more to society than ever before. This would certainly never have happened without BFT.

Simon's improvement in recent times has helped us to forget the many difficult times of the past, but we have to remember that our aspirations for him in life have changed dramatically since he was a schoolboy of potential. Also the knowledge of mental health that we have developed through BFT means that we have to remind ourselves from time to time that relapse is not impossible. However, it is now so easy to say that we are so pleased for him that he is able to get a quality of life that we never thought possible a few years ago. We are also proud of him in what he has achieved and coped with.

My Feelings about BFT – As Written by Mum

When BFT was first suggested to me, I was both nervous and happy to join the programme, mainly because I was desperate for someone to talk to who had professional knowledge of my son's illness. Even so, I worried about being in a situation of discussing mental illness and treatments whilst my son was present as I did not want him to be upset or annoyed with us for discussing him or an illness which he did not believe he had.

As the time approached for our BFT programme to start, my anxiety increased, worrying about his reactions; however, it became necessary for him to be sectioned, and we were told that we would be able to start without him and as soon as he was well enough he would be able to join us.

So we started without him, covering the modules concerning the different medications and treatments available. I found these discussions very helpful and interesting and could take part quite calmly, but often, unaccountably, I would find it very difficult to keep my emotions under control. I would squeeze my fingernails into my palms to stop myself from crying. I wanted to appear 'grown-up' and civilised about our discussions, but the effect of having lived with Simon and his illness for years, coping with him and his behaviour, making allowances for him and being careful not to let him see me looking at him, bubbled to the surface in the company of our caring and supportive team. I had firmly avoided crying, as I thought that it was a luxury I could not afford; I felt that if I once started I would never be able to stop. As a result, I had chosen not to discuss my son's illness outside the family and indeed my work colleagues were not aware of the way in which my husband and I were living. We slept in turns at night, as this was always Simon's worst time. He could not sleep and wandered the landing talking and discussing scenarios we would have been better not to have heard. Talking all this through during our BFT sessions was difficult, but our team handled it in a very patient way and guided us back to practical issues giving us coping strategies. I felt that with knowledge came acceptance, and with acceptance came the power to cope.

Simon first agreed to join us in our meetings, only because he liked the idea of an evening out of the hospital, and also the promise of a Chinese take away. He would stay in the meeting for a very short period of time, just long enough to qualify for the 'take away', and during this time, it was important that he and I were positioned so that he did not have to look at me. (Simon thought that my eyes had a power over him, and this made him uncomfortable.) We believe that he did listen to our discussions, but he rarely joined in, and when he had enough he would get up and leave the room. However, little by little he began to join in, and when he did, what he had to say was always a revelation to us all. We had our setbacks of course, but we continued with the meetings, as they were tailored to suit Simon's progress and ours. It has been a very long journey, fraught with emotion at times, but when the day came when we realised that he had regained cognitive thought, and he began to be able to speak with clarity and intelligence, which was such a joy to all of us.

I looked forward to our BFT meetings and knew that I had a very supporting team with whom I could discuss each new problem and with their help find a way of handling it. Indeed my husband and I feel very strongly that we would not have the life we have if it were not for our BFT team.

Simon's Perspectives

When I talked to Simon about BFT and asked him to reflect on what he thought about BFT, it was perhaps not surprising that he only really wanted to recall the more recent meetings when we have spent a lot of time talking about his activities and generally moving his life forward.

He was reluctant to give his perspectives on whether he had found it helpful during the more difficult periods of his illness although he acknowledged that we (Mum and Dad) had found it helpful and he did not have any problem with that. At no stage did he have any negative feelings about BFT but he chose not to recognise any benefits he had gained in terms of communications skills and other parts of the course.

These are some of the phrases he used:

- BFT was OK.
- You [Mum and Dad] seemed to like it and that was OK with me.
- I liked reviewing what I had been doing over the past weeks.
- BFT seemed to make things happen.
- The problem solving was good in looking at my sport and leisure activities.
- Helped me to arrange things for myself.
- The Chinese meal was good!

The Perspectives of the Therapists

The first two therapists that we had were Simon's social worker and community nurse and they remained with the programme as a pair for around 3 years, which was the really critical period. These are some of the phrases they used to describe our BFT programme:

• Simon was one of the most disabled patients either of us had encountered.

- We learned so much about Simon and the family from the BFT sessions which helped us considerably in assessing how we could best help each member of the family.
- For both of us, you were our first family and so we went through the journey together.
- We had to adapt the model and be very flexible in the way we delivered it in order to encourage Simon to join in.
- Although both Mum and Dad were receptive, Mum found it easier to engage because she really needed the support that this programme gave.
- Dad was more difficult because he thought it was theoretical, but once he realised the communications aspects were helpful to him at work he engaged much more easily he liked the practical benefits.
- The training gave me the tools the family taught me how to adapt the equipment.
- My initial perceptions of Simon were so wrong once he started to communicate with us.
- We were able to collaborate with Mum and Dad in helping Simon together.
- It was amazing how Simon would suddenly start to talk lucidly within the BFT sessions, whilst outside of these meetings he was reluctant to talk to parents or his care teams.

Final Messages

I hope that from this chapter it can be seen how much we as a family have benefited and continue to benefit from the family intervention that we were fortunate enough to undertake. As I go around the world of mental health, it has been a constant disappointment to me to discover how relatively few families have been offered BFT or similar type family intervention. I am very aware of all the obstacles that there are to implementation with families, but I do sometimes wonder whether the efforts to overcome these obstacles have been determined enough.

My hope is that readers who have got this far in reading my chapter are likely to be committed therapists and not just professionals who are looking to able to include the term 'Trained Family Therapist' on their CV.

Finally, please remember that family member carers are, in the main, lifetime project managers and want to help and be involved in the care of their loved one – BFT can help to achieve this.

18

A Casebook of Family Interventions for Psychosis

Reflections for readers implementing family work:

- The need to be flexible when the service user does not wish to become involved at the outset the therapists handled this.
- The issue of family workers also being case managers. Some clinicians feel that this is not appropriate, but it was really helpful in our situation and provided continuity.
- The importance of flexibility and negotiation throughout, for example agreeing how long Simon was able to stay in meetings.
- Simon as service user was able to chair family meetings and take notes when he was given the opportunity to do so.
- The importance of family meetings.

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