The painful spot: psychological support for the couple relationship when parenting children with undiagnosed genetic syndromes (SWAN)

Amy Hunter*, Holly Baker, Kym Winter, Chris Vincent, Joe Keenan

Genetic Alliance UK, Open University, Rareminds, independent, Manchester Metropolitan University

Background

Many children with syndromic conditions remain undiagnosed, despite progress with genomic technology. This is known as SWAN or syndrome without a name. The number of children with SWAN born annually is probably in the thousands in the UK alone, and the national support group SWAN UK currently has 4,000 families registered for their services.

The complexity and severity of undiagnosed children's needs can place huge stress on their parents. There is also uncertainty about children's development or the chances of deterioration or death. Being undiagnosed is isolating because there is no diagnostic label on which parents can base their communication with family, friends and professionals.

A healthy couple relationship is an emotional resource for the parents and the child – without it, families can start to unravel. The health and social care system in place for children in the UK does not offer parents psychological support so Genetic Alliance UK works with the community interest company Rareminds to provide couples counselling for parents with an undiagnosed child, free of charge. We find that demand far outstrips supply.

Methods

Ethical approval for the study was granted by Manchester Metropolitan University research ethics committee (Ethos ID 50777). Semi-structured interviews were carried out online with a) three couples who had completed a course of at least six counselling sessions delivered by Rareminds (each couple attended a single interview together), and b) three therapists who had each provided at least four full courses of the counselling. A thematic analysis approach was taken to assess the views of the parents/carers and therapists

Findings

Parents' experiences with their children

Parenting a child with special needs

Parents have to re-arrange their lives and re-imagine their futures. They must learn how to navigate 'the system' (health, education and social care) and can find themselves battling to get their child's needs recognised and to secure necessary support. The administrative and caring responsibilities placed on the parents can be huge. It can be an extremely isolating and stressful experience that impacts parents, their relationship with each other and the life of the wider family.

Caring for the carers

Despite the absolute dependence of children with SWAN on their parents/carers for their care needs, there is no systematic provision of support for the parents/carers. The Rareminds counselling offer is perceived as a validation of their need for support and provides a space to focus on the couple – to allow the relationship to continue as an emotional resource for the child and the parents themselves.

> *You end up fighting battles that I didn't even know... existed, you know, like, I had no idea, just no idea. And so that just brings an enormous amount of strain and stress, you know, onto a [couple's] dynamic that wouldn't have had that strain and stress.*

> *That's the point that I tried to make to social care as well, I said 'but hold on a minute, why can we not talk about the impact on us and our needs because if we're not meeting her needs then nobody is'*

> *Even in a thing as simple as feeding and just getting up and his emotional dysregulation; everything just takes so much time. So we hardly have any time for, as a family, let alone each other.*

Sources of support

Parents' views of support

Peer support only goes so far for parents in this situation, and finding appropriate, affordable private therapy is extremely hard.

Benefits of counselling

Couples reported positive impacts of the counselling on themselves as individuals, on their relationship, and the wider family.

> *I think if we hadn't done [the counselling] I think we would have had less ability to find a way to be at one, be together and be on the same team.*

> *There was a specialist playgroup...you learn from other people, but it's not always that supportive, because everybody's got their own battles and everyone's got their own difficulties that they're facing.*

> *The counsellor has helped me sort of put into words feelings and my emotions that I haven't been able to say myself.*

Therapists' views of Rareminds counselling

The painful spot

The depth and intensity of the painful issues in the parents' lives are varied and quite extreme. The therapists' role is to draw out the things the couple do not want to talk about, the 'painful spot', to get them to look together at the unthinkable, without judgement. There is a balance between getting to this in a short space of time, given the constraints of the service, and not pushing too fast or too far.

The power of therapy

The therapists have a strong sense of the value to parents of being heard and validated, and this results in very engaged and constructive sessions.

> *The difficult bit was...finding the painful spot for the clients, for the couple, finding the painful spot that was not being spoken about, but got in the way of the couple communicating with each other.*

> *They're often very, very engaged – they want to work and ... they get a lot from it, because they're not having to fight for it, unlike everything else in their lives. And I suppose it's also about somebody acknowledging the position that they're in and hearing them without fighting them.*

Conclusions

Our findings draw out themes which highlight the pressure that is placed on couples and the positive impact of the counselling on parents as individuals, on their communication as a couple, and on other dynamics in the family. Therapists reflected on the distinct nature of this client group and the challenges in drawing out the painful but important issues ('the painful spot') facing them. The counselling ensures that couples feel heard, understood and respected, and allows them to develop new ways of thinking about difficult couple dynamics and potential coping strategies.

Acknowledgements We would like to thank all the couples and therapists who gave their time to take part in interviews.

*amy.hunter@geneticalliance.org.uk