

The cost of caregiving

The first of a new series focusing on the person in psychological research and practice

The aim

Without people, there would be very little psychological research. Yet too often the individual is reduced to a data point, and we forget that the person has a voice, is changed by participation in psychological research and has the potential to impact upon the process in return. In this series we hope to address that, by hearing the viewpoints of those who have conducted published psychological research, those who have taken part in it and those who may put those findings into practice.

contribute

We want to hear the stories of those who have taken part in published research. Contact the Associate Editor, Dr Catherine Loveday, on C.Loveday@wmin.ac.uk.

resources

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The researchers

The study of caregivers has become a well-established paradigm for assessing the psychophysiological consequences of chronic stress and a number of studies have observed greater psychological distress, dysregulated endocrine activity and reduced immune efficacy in elderly caregiver cohorts. The study of parental caregivers of children has, by comparison, been a relatively understudied area. Parents of children with autism face tremendous physical, financial, emotional and social pressures and these can lead to prolonged activation of stress responses, which might place them at greater risk of adverse health outcomes. The consequences of these effects are far-reaching, and can influence the ability of the caregiver to provide consistent, effective and sustainable care for their child.

In our research, we found that caregivers of children with autism reported markedly greater levels of depression, anxiety and perceived stress and greater incidences of commonly occurring ailments, such as coughs, colds, headaches, etc., compared with parents of typically developing children. This may not sound too surprising especially given that the caregiver paradigm is founded on high levels of distress in caregiver cohorts; however, caregivers also differed in levels of biological parameters. In particular, they had higher levels of C-reactive protein (CRP) which is a marker of inflammation. Although the levels we observed would not be considered clinically elevated, high levels of CRP is a risk factor for cardiovascular-related diseases and has also been linked to diabetes.

We also measured levels of social support. Caregivers felt that they received less social support than parent controls, but, more interestingly, within the caregiver cohort, greater perceived availability of social support was related to reduced distress, fewer health complaints and more adaptive endocrine function. These results suggest that levels of social support may buffer against the harmful effects of stress.

Our results provide further evidence that stress can "get inside the body" through biological pathways and lead to negative health outcomes; however, social support may help to reduce its impact. Social support has been identified as a potential stress buffer in a variety of other contexts; for example, men demonstrate reduced stress responses when facing a stressor when their partner is present, and women who report greater levels of support from their partner secrete greater levels of the hormone oxytocin – "the tend and befriend hormone".

As for how our research could inform practice, the well-being of a caregiver goes hand in hand with quality of life of the care recipient; therefore, by identifying factors that might buffer the harmful effects of stress in the carer, we can improve quality of life for the care recipient. The fact that social support can be beneficial to carers may not be new to people who already deliver care and resources to the families of children with autism; however, these findings

demonstrate its potential buffering effect in terms of health and markers of disease vulnerability. We would, therefore, hope that the findings could spark the development of initiatives aimed at greater utilisation of social support, both practical and emotional, to carers and their families.

We're always looking to collaborate with other areas within psychology. The development and delivery of relevant interventions that can

alleviate the burden associated with stress in caregivers would be the next logical step in this programme and the findings regarding social support provide a logical area for development. Health and clinical psychologists and others experienced in the development of effective interventions would, therefore, make a valuable contribution to this next step.



Brian Lovell and Dr Mark Wetherell, Stress Research Group, Northumbria University

The carer – Claire Sowerby

Being responsible for a daughter with autism is all-encompassing. It can be wonderful, because my child has such a unique perspective on life, is loyal, can be helpful and kind and in a lot of ways quite straightforward. The hard part is other people making judgements about me and my child, because they do not understand her differences and think I can change her, or she can change in ways she cannot. It makes life very stressful, and my world has shrunk, so that there are only a few people in it. The ones left are those who try to understand or are in the same position. My daughter has withdrawn socially outside of school. I now find it's easier to "go with the flow" and withdraw with her, than hope to go and do things we used to do.

Having ASD means she will not follow a clear development towards independence, which parents of a non-disabled child plan for. Therefore my life will not follow the cycle others can expect. Because she is on the autistic spectrum (rather than having a clearly defined label of autism) I have never been entitled to any respite and do not expect any future intervention or support in her future life plans. I have given up hope of having a relationship. I cannot go out socially (apart from when my child is at school) or plan for a future with anyone when everything is so uncertain.

My daughter's development is age-appropriate in some ways, for example wanting to wear make up or watch "15" films, but then not in many other ways, such as not going out with peers, instead being dependent on me for all her social needs and watching *Teletubbies*. I do not know how independent my child will ever be and cannot make future plans in which she is not central to these. I don't know if she will have a partner or family (she says she would love children). If she did have a child, would she be able to look after it? Will she be able to work? Go out without

being taken advantage of?

I am a qualified nurse practitioner but no longer work. I could not work the hours required in this type of job or at that level of responsibility now. I did have other jobs in clerical/teaching support assistant type work more recently, but have had to finish all of those jobs due to lack of childcare, stress and lack of employer flexibility. My daughter was placed in an inappropriate school environment and became highly stressed, developed risk-taking behaviour and refused to go to school. I spent three and a half years writing letters, keeping diaries, appealing against statements to get her moved, which meant that work was out of the question. Her non-autistic sister developed issues too, as we were living in a very volatile situation, and this impacted on her mental health.

There is and has been no childcare appropriate to the age and needs of my child (who is now 15). She cannot be left on her own as she is too vulnerable. I have tried to share care with other parents in a similar position, but because autistic children are used to everyone in the house bending to their needs, they often do not like someone else in the house trying to get on the computer or touching their things. It is horrible being dependent on benefits. It makes me feel very vulnerable, particularly when there are to be cuts to benefits and they have to be reapplied for over and over again (e.g. disability benefit). Having to give up so many jobs has knocked my confidence and I hate being judged by society. I want to work but cannot leave my child alone and do not know of any time in the future that I can. Financially things are difficult, for example replacing broken electrical



equipment, providing luxury items, like holidays, etc.

Participating in the research project with Northumbria University was nerve-racking when I first went there, but I

was put at ease by the staff. Everything was explained clearly and was fairly simple to do. I was disappointed more parents did not get involved, as I think this research is valuable to us. Without evidence, how will our stress and the costs of that stress (financially, emotionally and socially) ever be recognised?

I was pleased to be provided with the findings of the research, as I felt it validated my experiences. It helped me feel less alone and inadequate, knowing other parents were exhibiting similar stress reactions.

I would be interested to know of any other relevant research that has been done, and would be happy to take part in other research. The only intervention I have had is when things have reached a crisis. This can make you feel inadequate, when the rest of the time you may have coped very well under very difficult circumstances. It would be good if there was more preventative type of help for parents, e.g. a supporter of some sort being available once a month/every few months to see and talk to about all the issues dealt with successfully (so you feel more empowered and strengths are recognised) and those that are a worry, to prevent these issues becoming critical. A friend told me about emotionally focused therapy, which she found helpful, and I think it would be a good technique I could use to reduce stress levels. Also maybe I would benefit from being taught meditation.'

Conducting this research has inevitably taught us a bit about what it's like to look after someone. If you're a parent, you'll be very aware of the ups and downs of parenting and the benefits of having good social support. What is striking in our meetings is the consistent delivery of care that these parents provide their children, despite their extremely high levels of psychological distress and a perceived unavailability of the social support that they think they need.'

The health professionals

What are the most frequent difficulties or anxieties that carers talk to you about?

One of the major anxieties carers express is the uncertainty around how their child's diagnosis of autism may affect their child in the future and what impact this will have on their development. Associated with this are their anxieties around future service provision, managing transitions,

independent living and future employment prospects. Families will often describe having anxieties in relation to managing certain behaviours without this having a detrimental impact on their ability to participate in social activities. Anxieties in relation to educational provision are often centred on how to communicate the diagnosis, how to negotiate further support for their child

viewpoints

and how to choose which educational provision will best support their child.

How do you feel about psychologists wanting to carry out research with people caring for a child with autism? Working in a Child and Adolescent Mental Health Service it is important that we are providing a service that is evidence-based and that families feel well supported by. Conducting research with carers can provide rich and detailed information based on real experiences, which is invaluable. This research can then inform future policies, guidelines and practice to ensure that evidence-based services are being provided. The importance of this is highlighted in the Autism NICE guidelines (2011), which state that treatment and care should take into account the preferences and needs of both the young person and their carers. Carrying out research with carers is therefore providing them with an opportunity to make their preferences and needs heard and for this to impact on service delivery.

What do you think of the recent findings and can you envisage how this might help to inform carers and those

supporting them?

This research has provided carers with an opportunity to reflect on these findings, perhaps giving them permission to acknowledge and voice thoughts and feelings that may have felt too difficult to acknowledge previously. Furthermore, by highlighting the impact of caregiving it normalises this experience as it is shared by others in similar situations. This research has also emphasised to services that there needs to be greater consideration given to the impact that caring can have on an individual and that this should be discussed openly with carers. This research further identifies a role for services to spend time with carers identifying social support and ensuring that the treatment plan encompasses the carer's needs as well as the child's.

Are there any other ways the psychology profession could inform or support people caring for a child with autism?

Following diagnosis, psychologists have

the important role of listening to and containing carers' initial anxieties as well as helping families to make sense of a diagnosis. Furthermore, they can make parents aware of the impact that caregiving can have on their own emotional well-being and encourage the use of social support and respite, and signpost them to other agencies.

Psychologists can play a key role in supporting carers in developing strategies for managing difficulties, promoting skill learning and maximising the child's strengths. Psychologists can also develop and deliver therapeutic and psycho-educational groups about autism, comorbid mental health difficulties and behavioural interventions. Their involvement in planning services and organising multi-agency pathways can ensure that carers feel well supported by different services. Furthermore, they can offer teaching, training and supervision to professionals and services who work with carers, ensuring that a high level of support is being provided.

*Dr Laura Rollison and
Dr Catherine Wright*

Child & Adolescent Mental Health Services

"Conducting research with carers can provide rich and detailed information"

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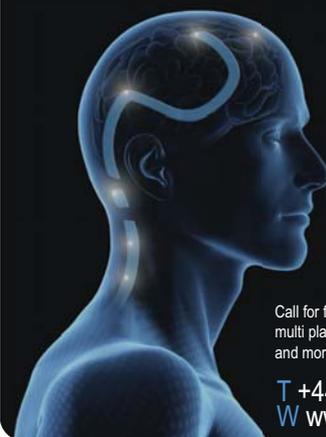
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