

ORIGINAL RESEARCH

Chronic sorrow in parents of children with type 1 diabetes

Susan Bowes, Lesley Lowes, Justin Warner & John W. Gregory

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Correspondence to S. Bowes:
e-mail: susie_bowes@hotmail.com

Susan Bowes BN Msc RN
Paediatric Diabetes Specialist Nurse
University Hospital of Wales, Cardiff, UK

Lesley Lowes PhD RGN RSCN
Senior Lecturer Practitioner in Paediatric
Diabetes
Nursing, Health and Social Care Research
Centre, Cardiff University, UK

Justin Warner BSc MBBCh MD
Consultant in Paediatric Endocrinology
and Diabetes
University Hospital of Wales, Cardiff, UK

John W. Gregory MBChB MD FRCP
Professor in Paediatric Endocrinology
Cardiff University, UK

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Abstract

Title. Chronic sorrow in parents of children with type 1 diabetes.

Aim. This paper reports on a study exploring parents' longer-term experiences of having a child with type 1 diabetes.

Background. Parents of children with type 1 diabetes may experience a grief reaction at diagnosis similar to that normally associated with bereavement, but little is known about their long-term emotional adaptation. Chronic sorrow, a sustained but intermittent grief reaction, is identified in adults with diabetes but has not previously been explored in relation to parents.

Methodology. In-depth interviews were conducted in 2007 with a convenience sample of 17 parents of children with type 1 diabetes 7–10 years after diagnosis. Data were explored within a theoretical framework of grief, loss, adaptation, and change.

Findings. Parents had adapted to the needs of diabetes management but most had not 'come to terms' with the diagnosis. They experienced a resurgence of grief at critical times during their child's development and some, particularly mothers, became upset during their interviews, even though these took place 7–10 years after their child's diagnosis. Mothers elaborated more on their emotions than fathers, but continuing feelings associated with grief, such as anger and guilt, were expressed by both fathers and mothers.

Conclusion. Greater understanding of parents' long-term emotional responses and recognition that grief may never resolve in these parents may enable healthcare professionals to provide appropriate and timely support at critical times.

Keywords: adaptation, children, chronic sorrow, nursing, parents, qualitative research, type 1 diabetes

Introduction

The incidence and prevalence of diabetes in children and young people is increasing worldwide at a rate of 2–5% (International Diabetes Federation 2007, Diamond Project Group 2006), with an estimated 440,000 children worldwide having type 1 diabetes. The United Kingdom (UK) has also

seen an increase in occurrence of children diagnosed with type 1 diabetes (SIGN 2001). Approximately 25,000 people under the age of 25 years in the UK have type 1 diabetes (NHS Information Centre 2007), making it one of the most common chronic childhood conditions. Type 1 diabetes is characterized by a complex and invasive management regimen that has a physical and psychological toll on the whole

family (Lowes *et al.* 2004). Management of type 1 diabetes comprises 2–4 daily insulin injections or administration using an insulin pump, blood glucose monitoring, regular meal planning and physical activity. Knowledge of the complexities of diabetes management is essential to enable families, particularly parents, to help children acquire the skills for diabetes self-management (Sousa *et al.* 2004, 2005, 2008). Despite improved management regimens, there is still risk for significant morbidity, e.g. poor glycaemic control is known to increase the risk of long-term complications of diabetic retinopathy, nephropathy and neuropathy (Diabetes Control and Complications Trial Research Group, 1993) and parents are aware of, and may have to cope with, the acute life-threatening complications of hypoglycaemia and diabetic ketoacidosis.

Background

Grief

Parents whose children are diagnosed with type 1 diabetes have been found to experience an initial grief reaction similar to that usually associated with bereavement (Kovacs *et al.* 1985, Hatton *et al.* 1995, Lowes *et al.* 2004, 2005). They describe a range of emotions at diagnosis such as shock, denial, anxiety, sadness, anger, guilt and frustration (Kovacs *et al.* 1985, Hatton *et al.* 1995, Eakes *et al.* 1998, Lowes *et al.* 2004), and have been found to experience a number of losses incurred by the diagnosis, such as loss of spontaneity, loss of freedom and loss of their child's health, up to 12 months after diagnosis (Lowes *et al.* 2004, 2005).

A number of theorists propose that there is a time-bound linear trajectory through the grieving process that eventually results in an endpoint such as resolution or acceptance (Kubler-Ross 1970, Kumm 1985, Copley & Bodensteiner 1987, Clubb 1991, Worden 1995). Indeed, Kovacs *et al.* (1985) suggest that parents usually adapt to or accept their 'losses' within the first year of diagnosis. However, Eakes *et al.* (1998) argue that individuals never reach the acceptance stage because specific events trigger memories that remind them of their losses. These emotions vary in intensity, periodically fading and re-emerging, which is characteristic of a concept known as 'chronic sorrow' (Olshanky 1962, Fraley 1986, Eiser 1990, Clubb 1991, Teel 1991, Burke *et al.* 1992).

Chronic sorrow

Olshanky (1962) introduced the concept of chronic sorrow to explain the response of lifelong episodic sadness in parents of

children with impaired cognitive abilities. He suggested that parents of chronically ill children never reach the closure stage of time-bound models, as parents never fully recover from the impact stage. He also believed that feelings of guilt are not eliminated and, although parents adjust and adapt to the situation, their efforts do not represent acceptance (Lowes & Lyne 2000).

Olshanky's conceptualization of chronic sorrow was supported by Wikler *et al.* (1981), who examined whether time-bound theories or chronic sorrow more closely described parental reaction to children with impaired cognitive abilities. Results showed that most parents depicted a life of 'ups and downs', with a higher level of grief later in the child's life compared with the grief experienced at diagnosis, which may be related to the more noticeable difference in the children's abilities as they grew older when compared with the normal developmental abilities of healthy children (Clubb 1991). Repeatedly, over time, these parents are forced to face the reality that their children are different.

Emotional adaptation

Little is known, however, about the grieving process experienced by parents of children with type 1 diabetes in the long-term. It is debatable whether these parents ever accept or come to terms with the diagnosis. However, studies examining parental experience have commonly been undertaken in the first year after diagnosis (Kovacs *et al.* 1985, Hatton *et al.* 1995, Lowes *et al.* 2004, 2005), with one carried out only 6–8 weeks after diagnosis (Landolt *et al.* 2002).

The study

Aim

The aim of the study was to explore parents' longer-term experiences of having a child with type 1 diabetes.

The specific objectives were to:

- Explore parental emotional adaptation to childhood diabetes 7–10 years after diagnosis.
- Elicit whether parents experience the periodic resurgence of grief that characterizes chronic sorrow.
- Examine whether emotional adjustment differs between fathers and mothers.

Design

A qualitative study was carried out, using in-depth interviews for data collection.

Participants

The participants were a convenience sample of 17 parents (10 mothers, 7 fathers) whose children (now aged 9–23 years) were diagnosed with type 1 diabetes 7–10 years previously. The sample provided a wide range of characteristics, e.g. single parents, children of different ages, to elicit a rich account of their experiences of living with a child with diabetes. Parents of children with co-existing chronic disorders (e.g. cystic fibrosis) were excluded because of their experiential knowledge of coping with childhood chronic illness. Participants were recruited from one large National Health Service centre in Wales.

Data collection

Thirty-eight parents who fulfilled the study inclusion criteria were identified by Paediatric Diabetes Specialist Nurses (PDSNs). A study information sheet and a consent form were sent to them to sign and return if they agreed to be contacted by the researcher. Nineteen parents returned consent forms indicating an interest in participating in the study. The researcher telephoned the participants to arrange a convenient interview time and venue. Two parents were unavailable for interview and thus the final sample comprised 17 parents.

Fathers and mothers were interviewed separately to enable comparison of data between maternal and paternal responses (Jerrett 1994). However, joint interviews were undertaken with parents from two families who chose not to be interviewed separately. Thus, 15 in-depth, audio-taped interviews were undertaken with parents ($n = 17$) between January and May 2007 by one interviewer (SB). Thirteen interviews were conducted in parents' homes and two were undertaken at the hospital at the parents' request.

Interviews focused on parents' experiences of caring for a child with diabetes over the last 7–10 years. An initial open-ended question asked them to 'Describe your experience of having a child with type 1 diabetes', with subsequent questions addressing how the parents' experience had changed over time since their child's diagnosis. Although an interview guide was developed from existing literature, many parents enlarged upon anticipated topics naturally in spontaneous individual accounts while recalling their experiences, and only minimal prompting was needed.

Ethical considerations

This study was approved by the appropriate ethics committee. Parents were informed of the specific objectives of the study and written consent was obtained. Assurances of

confidentiality in relation to the data, publications and presentations were given, and participants were told that they could withdraw from the study at any time without giving a reason. Due to the emotive nature of the research, they were also informed that a contact phone number for a parent counsellor was available if they felt this was necessary; however, no participant requested this.

Data analysis

Interviews were transcribed verbatim. Data were coded into categories and explored within a theoretical framework of grief, loss, adaptation and change, to elicit whether or not the parents' experiences included any characteristics of the various grief theories, such as acceptance, resolution and the periodic resurgence of grief that characterizes chronic sorrow (Olshanky 1962, Kubler-Ross 1970, Copley & Bodensteiner 1987, Worden 1995). Data were also explored to uncover whether emotional adjustment differed between fathers and mothers. We continually reviewed, discussed and challenged analysis of the data. All decisions concerning data interpretation were justified with reference to the original text and the data examined for similarities and differences between cases and for divergent cases, i.e. those that differed in important respects from the majority. Thus, criteria for the conduct of qualitative enquiry were strictly observed (Ashworth 1987, Pope *et al.* 2000).

Findings

Numbers and codes are used below to identify participants (i.e. *M* = mother, *F* = father, interview number, son/daughter), and children's ages not identified to ensure anonymity (Data Protection Act 1998).

Study limitations

This qualitative study was conducted at a single site with participants mainly being professional people. Parents who did not participate may have had different experiences. However, the findings add to a body of knowledge about chronic sorrow in a population previously unexplored in this context.

Revisiting diagnosis

When parents were asked to describe their experiences of having a child with diabetes over the last 7–10 years, they all began with how they felt at diagnosis, most describing feelings similar to those associated with grief. Two mothers and one father said they blamed themselves for their child's diabetes:

I blamed myself because it came through my mother's side of the family, so it was a real shock in the beginning (M8: son)

We did go within ourselves a bit because we were blaming ourselves due to guilt. We thought it was our fault that they had it (F5: daughter and son)

Parents found the practical management of diabetes difficult to deal with at first, but over time they became accustomed to the daily tasks and accepted the routine as part of their lives:

The first few goes (injections) you think, 'Oh my god' this is really something horrible to do, but now you don't think twice about it (F7: son)

[Diabetes] is not a handicap any more. In the early years, she saw herself as different, lacked confidence and saw herself as inferior. As time passes, you relax and realise that you can manage with flexibility (M1: daughter)

However, the data suggest that many parents had never really 'accepted' the diagnosis:

It's been nearly 11 years since diagnosis and if I'm honest I still haven't come to terms with it. I've accommodated it but not really come to terms with it (F4: son)

I still blame myself now. I overcompensate and I suppose you make allowances because of the way he is. You sort of take his side more than you should (M8: son)

It was difficult for me to come to terms with, the fact that I didn't want to carry on, even now it kills me to talk about it...the anger will always be with me (M3: son)

Many years after diagnosis, two fathers experienced self-remorse if they had not thought of their child in relation to diabetes during the day:

I went out for the day to watch the rugby and it wasn't until I was coming back that I felt guilty as I'd not remembered or worried about it while I was out (F1: son)

Triggers that evoked a resurgence of parental grief

Although parents did not feel sad most of the time, definite triggers that induced recurring feelings of sadness were identified from their accounts, e.g. hospitalization, adolescence, injections and transition. Most were still experiencing these feelings up to the time of interview. Indeed, four mothers and two fathers became distressed when talking about specific events relating to their child's life with diabetes, with two maternal interviews needing to be temporarily paused.

Insulin injections

Some parents (mainly mothers) still found it upsetting to watch or give their child their injections:

We haven't given any injections but it still hurts me when I see him inject himself (M3: son)

Suddenly it will come out of nowhere – the enormity that it will never go away, you live with it every day and it is things like seeing him inject in the morning and he's got to do that every single day (F4: son)

Illness or hospitalization

Periods of illness or re-admission to hospital particularly caused a resurgence of grief for parents, because these brought back memories of when their child was first diagnosed:

Sometimes when they're having their injections or they're ill, it gives me flashbacks...Having to go back into hospital brought back a lot of feelings (M7: daughter)

Hospitalisation is upsetting because you can't do anything for her, thinking why is it happening to her and not anyone else? (F5: daughter)

When he has been readmitted, there is the sense of worry and fear. There's guilt – if I'd done something right then he wouldn't be in here (F4: son)

Diabetes control

Most parents reported that diabetes management and their knowledge of the consequences of poor control caused continuing stress and anxiety many years after diagnosis, which seemed to inhibit closure concerning their child's diagnosis. Emotions resurfaced if the child's diabetes went out of control:

You never stop worrying, even after all these years I still worry. Now he's older there's the real fear of something happening, but I don't think I'll ever get over that (M6: son)

We've had issues with drinking and she's learnt the hard way...she's gone through phases of not doing her insulin in order to lose weight...her teenage years are very turbulent. This has caused stress with our relationship (M10: daughter)

I feel frustrated because something totally out of her control can spoil it for her. It's not that simple. It may look good on paper, this is what you do, but there are times when it all goes out the window, and that's when I find it hard (M4: daughter)

I did not handle it very well, as every high reading he had I felt guilty (M3: son)

Risk of complications

Although the risk of their child developing future complications was not thought about constantly, parents remained concerned and upset about their child's future health:

We fear the future...you do ease off a bit but it's a serious disease...you lighten it a bit otherwise you wouldn't manage and you would get complacent. A lot of the TV shows show the serious side of the disease and that's when it hits home, that it could happen if you didn't stay in control (F1: son)

When I read about it in the news, I often think I'll hide that from him because it's upsetting. There's a person in our church who has had his leg amputated and I think I won't tell him that. That kind of thing is quite a worry. I don't know how aware he is. That's quite upsetting even now (M5: son)

Participant F7 described how the family dealt with this emotional trigger – by taking it as 'blocks in time' – once they got through one stage, they tackled the next. M2 manages by not dwelling on the future, which she saw as a long way off. Similarly, F4 blanks thoughts of the future, as he cannot deal with it, even though he knows the reality is that complications will probably occur at some point in his child's life.

Letting go

Parents (mainly mothers) whose children were diagnosed at a young age found it difficult to resign diabetes care to their children once they had reached adolescence/adulthood. They had provided a high level of care and supervision since diagnosis, and encouraging independence made them feel that they were no longer in control:

When I was managing the diabetes I had 'control', I made it live with us and not live with it, you have to adapt (M10: daughter)

As they get older, we [parents] were not in control of their life and they have to take control themselves, but that doesn't stop you worrying (M6: son)

I was watching from the side lines...unfortunately she wasn't monitoring herself as well as she should have been...as a parent it's very difficult to switch off...you weren't thinking about it all the time, it was there in the background (M1: daughter)

Transition from the paediatric to adult diabetes service

In a similar way, their child's transfer to the adult service was an emotional trigger for parents, as they realized a further loss of control in relation to their child's diabetes. All those whose children had transferred to the adult service felt a sense of sadness at leaving the familiarity of the paediatric service, where they had been more involved in decisions about their

child's care. Two mothers described this as having the 'apron strings' cut:

I felt sad that we were leaving the paediatric clinic to go to the adult clinic. It was like having the 'apron strings' cut and the safety of everything taken away from you...you get attached really...you get to know your doctor and nurses...always there if you needed them. I'm on my own now and it's not as easy to pick up the phone. It's up to him now...I would have liked to have been in the background for the first adult clinic (M3: son)

I find it hard coming to clinic and sitting there and not being part of the consultation. I'm just the taxi driver...I do find it hard that there is no feedback to me afterwards, especially with some of the things that we have been dealing with recently, not taking her insulin and pretending to take it...she wasn't mature enough in my opinion and it's been one of the worst things to happen (M10: daughter)

Emotional support

Parents recognized the need for emotional support. However, all but one set of parents stated that no emotional support was provided by healthcare professionals. There were mixed feelings about when this support should be offered, with some thinking that it should be offered at the time of diagnosis, others believing that it would be beneficial later on, and some feeling that it should be on-going:

Concerns how I felt about it and felt alone. It would have helped to have talked about it (F4: son)

I think that emotional support should be offered throughout. I think it isn't offered because we [parents] are perceived as coping (M10: daughter)

Emotional support would be beneficial as an ongoing thing because initially you need a lot of support in that you don't really know what it is all about, what to do, and if you speak to other people they might say to try it this way or try it that way (M8: son)

Support needs to be there for the time they need it – so it needs to be ongoing. I'm sure lots of people need it a lot more at the beginning (M4: daughter)

Although parent support groups existed, many chose not to attend or did not find them particularly helpful:

I went to a parents' group, but I actually stopped going to it as I didn't find it beneficial (M4: daughter)

However, a few felt that support groups could help through sharing experiences and knowing that 'you are not alone':

I've met up with other mothers that have children with diabetes; that has been a tremendous help. You can relate to them, we are all going through the same things (M10: daughter)

Parental differences in expressing their feelings

During the interviews, mothers were far more likely than fathers to talk about their feelings. Mothers discussed their emotions and identified how specific events incurred continuing feelings of sadness:

The complications and that side of it doesn't ever go away at all. You just get good days and bad days when something's makes you think of it. Other days you can go for ages without thinking about it (M4: daughter)

Mothers were also more comfortable expressing their feelings in clinic and to other family members and friends, whereas, fathers said that they found communicating their feelings difficult:

I'm not able to talk to friends and family easily about my feelings, they tend to just build up... I don't want to burden my wife with my emotions as she's found it hard to deal with it herself...emotions build up, but you just have to cope (F6: son).

I feel that I can't say to them [family] that I find it a struggle. I just have to get on with it... I very rarely talk about it and this is the first time I've talked to anyone about it in years (F4: son)

Interestingly, some mothers commented that they only told their partners what they thought the latter could cope with. Up to 10 years after diagnosis, some parents had not discussed their feelings about their child having diabetes:

For years, I bottled things up and didn't sit down with my husband and talk about it as I didn't want to worry him. I actually thought, I can't believe I have taken this length of time and we have never discussed it (M4: daughter)

However, despite their ability to talk about their feelings, most mothers continued to experience emotional responses to their child's diagnosis. One stated that she became depressed because of the stress of her children having diabetes, but it is uncertain whether this mother had an increased risk of depression because two of her children were diagnosed with diabetes:

I used to blame myself for it, I still do now, and I think that has a part to play in my depression (M7: daughter and son)

Another mother had difficulties that were exacerbated by her husband's chronic illness and her concerns for his welfare:

Defences are low if my husband is unwell. I feel guilty, as I'm not allowed to feel sorry for myself or be ill. I have to get on with what's thrown at me (M3: son)

The data also suggested that having a child with diabetes could potentially affect marital relationships. Two sets of parents had separated, and both believed that the stress of their child having diabetes might have contributed to their difficulties.

Discussion

Theories of grief use various constructs to depict an endpoint to grief, such as 'coming to terms with', acceptance, adaptation and resolution (Kubler-Ross 1970, Copley & Bodensteiner 1987, Worden 1995). A review of the literature suggested that, although parents adapt to accommodate the needs of a child with diabetes, parental grief arising from the diagnosis may not resolve or reach an endpoint as proposed by time-bound models of grief (Lowe & Lyne 2000). This study was undertaken because previous studies have typically encompassed a timeframe of 6–12 months after diagnosis (Kovacs *et al.* 1985, Lowe *et al.* 2004, 2005), which, it could be argued, is insufficient to demonstrate the existence, or not, of chronic sorrow.

Our findings support the existence of chronic sorrow in parents of children with type 1 diabetes. The data indicate that grief experienced by parents in this study may not have an endpoint, and that they continue to experience intermittent grief, the characteristics of which are consistent with the concept of chronic sorrow. The data strongly suggest that none of the parents, apart from one father who also had type 1 diabetes had fully accepted the diagnosis or achieved closure. Closure for these parents seemed to be inhibited by a resurgence of feelings of grief at critical times in their child's life, such as readmission to hospital, which brings emotional responses at diagnosis to the forefront of their minds. Thus, although they had adapted their lives to encompass the demands of having a child with diabetes, these parents had not resolved their feelings of sadness arising from the diagnosis, even though all the diagnoses had occurred 7–10 years previously. This finding was exemplified by the four mothers and two fathers who were openly distressed when talking about their experiences during their interviews. Furthermore, Olshanky's (1962) belief that parental feelings of guilt endure over time, despite practical adaptation to the situation, is substantiated by the experiences of these parents.

Our findings, however, differ in one respect from work by Olshanky (1962) and Wikler *et al.* (1981), who found that parents of children with impaired cognitive abilities experienced a higher level of grief later in their children's lives than that experienced at diagnosis. This was not corroborated by parents' accounts in our study, probably due to children with type 1 diabetes having no difference in developmental ability when compared to unaffected children. Although parental

What is already known about this topic

- Parents of children with impaired cognitive ability are believed to experience a concept termed 'chronic sorrow' in response to their child's diagnosis.
- Chronic sorrow is a recurring sadness interwoven with periods of neutrality, satisfaction and happiness with no endpoint.
- Chronic sorrow has been identified in adults with diabetes, but has not been explored in relation to parents of children with type 1 diabetes.

What this paper adds

- Parents of children with type 1 diabetes experienced intermittent feelings of grief up to 10 years after diagnosis.
- Mothers were more able to talk about their emotions than fathers but continuing feelings associated with grief, such as anger and guilt, were experienced by both fathers and mothers.
- Parents' experiences corresponded with the characteristics of chronic sorrow.

Implications for practice and/or policy

- Healthcare professionals need to recognize that parents of children with type 1 diabetes may continue to experience episodes of grief for many years after diagnosis.
- Recognition that grief may never resolve in these parents will assist healthcare professionals to provide the necessary support at critical times.
- Emotional support for parents should be on-going and their psychological needs regularly reassessed.

feelings of intermittent sadness continued throughout the child's teenage years and into adulthood, parental grief did not seem as intense as that found to be experienced at diagnosis (Lowes *et al.* 2005).

Parental feelings of grief resurfaced because of a number of common triggers identified by parents in their accounts of their experiences. Transition from paediatric to adult services was a particularly difficult time for parents, whose children were now young adults. They experienced a sense of loss when their child moved from the familiarity of the paediatric team, and felt sidelined concerning their child's diabetes care. It is recommended that diabetes transitional care should be a gradual, therapeutic process for young people (Department of Health, 2001; Royal College of Nursing, 2004). However, the needs of parents, who have

taken responsibility for the management of their child's diabetes for many years and may provide continuing support into adulthood, do not seem to have been taken into account. Our findings suggest that parents need to be better prepared for their child's transition.

Although data from both mothers and fathers contributed to the finding that chronic sorrow is experienced by parents of children with type 1 diabetes, fathers were less likely to talk about their emotions. All the fathers said that they tended to keep their feelings to themselves, mainly because of not wanting to burden others, particularly their partners, who were themselves finding the situation 'hard to deal with'. Mothers, however, tended to talk about their emotions to friends and family (but not necessarily partners). Nevertheless, there was no evidence that sharing emotions helped mothers to come to terms with the diagnosis, perhaps due in part to mothers predominantly assuming responsibility for their children's diabetes care and seeing their children undertaking invasive procedures on a daily basis. Findings from other studies suggest that mothers may have more difficulty accepting their children's critical illnesses, which can lead to increased risk of depression and poor adaptation, therefore requiring a greater need for formal support services (Fralely 1986, Timiko *et al.* 1992).

However, an important finding from this study concerns parents' perception of a lack of emotional support from healthcare professionals. Although they felt supported by the clinical team in relation to the practicalities of diabetes management, there was an overwhelming belief that on-going emotional support should have been available as and when needed. Worryingly, some thought that emotional support was not offered because they were perceived as 'coping', which suggests that their emotional needs were not identified in the context of routine care. One father in particular felt that his psychological needs were not met, which may be due in part to fathers being inhibited about discussing emotional issues. Also, mothers typically take on the primary carer role (in this study, only one father was the main carer) and are more likely to be the parent accompanying their child to clinic, where emotional needs may be identified. The lack of psychological support identified by these parents might have occurred for five main reasons.

First, in most paediatric diabetes clinics, parents and children attend consultations together, and parents are probably reticent to discuss their emotional problems in front of their children. Second, clinic consultations are often necessarily short because of time restrictions and focus on the practicalities of diabetes management and improvement of glycaemic control. Parents' emotional needs are perhaps more likely to be identified during home visits by a PDSN rather than in busy

outpatient clinics. Third, if a child's HbA1c (a measure of glycaemic control over 6–8 weeks) is perceived as a measure of how well families are coping, underlying emotional problems may well be missed, particularly in parents whose children have good diabetes control. Fourth, many paediatric diabetes services do not have sufficient input from psychological services, because of resource implications and a shortage of child psychologists specializing in childhood diabetes (Hartnett 2005). Given that psychological disturbances (e.g. anxiety, depression, family conflict) arising from the presence of diabetes can have an impact on glycaemic control and the well-being of children and their families (Houghton 2004), national and international guidelines (International Society for Pediatric and Adolescent Diabetes 2008, Department of Health, 2004, National Institute for Clinical Excellence 2004; Diabetes UK 2005; Delamater 2007, American Diabetes Association 2008) emphasize the need for psychological support as an integral part of paediatric diabetes care.

Finally, although healthcare professionals have an awareness of the acute grief experienced by parents at the time of diagnosis, it is possible that chronic sorrow is unrecognized and, therefore, not addressed. Awareness of the existence of chronic sorrow could assist healthcare professionals to provide appropriate, timely emotional support to parents and reassure them that feelings of continuing sadness are not unusual. It is also important that healthcare professionals consider the needs of fathers as well as mothers when assessing emotional coping.

Conclusion

An important outcome from this study is identification of the need for provision of ongoing emotional support for parents, who may continue to experience episodes of grief for many years after diagnosis; the needs of fathers particularly need to be taken into consideration. Recognition that grief may never resolve in these parents will assist healthcare professionals to provide the necessary support at critical times.

Further research in this area could include investigations of the grieving process of children/young people with type 1 diabetes, and any correlation between parental long-term emotional adjustment and children's diabetes control.

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Conflict of interest

No conflict of interest has been declared by the authors.

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Author contributions

SB was responsible for the study conception and design, performed the data collection and also obtained funding. SB and LL performed the data analysis and were responsible for the drafting of the manuscript. JG, JW & LL made critical revisions to the paper for important intellectual content. LL supervised the study.

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