Social support for the parents of children with type 1 diabetes: An ethnographic study

Elaine Newell, Sinead Hahessy

The incidence of type 1 diabetes is on the rise, and it has become one of the most common chronic childhood conditions globally. Caring for children who have been diagnosed with type 1 diabetes has been shown to contribute to parental distress, owing to the chronic nature of the condition. In recent years, social support groups have been established to provide parents with an environment in which to share their experiences and advice. This article reports on the findings from an ethnographic study of a social support group in Ireland for parents who have children with type 1 diabetes, aiming to gain an understanding of the experiences of parents outside of the hospital setting, and the significance of these social support groups in diabetes care delivery.

Article points

1. The authors of this article completed an ethnographic study of the significance of a social support group for parents who have children with type 1 diabetes.

2. Through participant observation of the group meetings, semi-structured interviews and field notes, prominent themes emerged relating to the issues encountered by the parents and how they view the social support.

3. The group setting was observed to offer a sense of belonging, solidarity and equality, as well as allowing the exchange of "experiential knowledge", distinct from that offered by healthcare professionals.

Key words

- Ethnography
- Social support
- Type 1 diabetes

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Type 1 diabetes is one of the most common chronic childhood conditions globally with an estimated overall annual increase of approximately 3% (Green and Patterson, 2001). It is estimated that, on an annual basis, 70 000 children under 15 years of age will develop type 1 diabetes worldwide (International Diabetes Federation, 2007). van Belle et al (2011) argue that the incidence of type 1 diabetes is on the rise globally and theories are emerging that point to a complex epidemiological picture. Genetics offers some answers as to the increasing rates. However, other theories relate to the incidence of early childhood infection and child nutrition. Owing to the increasing numbers of young children diagnosed with type 1 diabetes, attention needs to be given to interventions that best support and meet the needs of both the children and their parents.

The precise prevalence of diabetes in Ireland is unknown as there is no diabetes register. Irish paediatricians and endocrinologists estimate that there are currently between 3000 and 4000 children, adolescents and young adults (aged 0–19 years) living with diabetes in Ireland, a majority of whom have type 1 diabetes (Irish Diabetes Prevalence Working Group, 2005).

In Ireland, children with type 1 diabetes attend a diabetes centre at least three times per year. Care is overseen in optimally staffed centres by an endocrinologist, paediatric DSN and dietitian, though this can be subject to variation. However, social support is neglected and parental support groups have developed in an *ad hoc* fashion. Currently, there are 10 support groups operating in Ireland for parents who have children with type 1 diabetes (Irish Diabetes Prevalence Working Group, 2005).

Study aims

Parental experiences of life with a child with type 1 diabetes are under-represented in the literature and there is a lack of research that focuses on identifying optimal support interventions for parents (Monaghan et al, 2011; Nurmi and Stieber-Roger, 2012). This study aimed

to describe the culture of a social support group for the parents of children with type 1 diabetes and elicit data that would offer an understanding of the parental experience. Knowledge of the challenges encountered by parents can inform nursing practice by providing awareness into the reality of daily life associated with managing the condition.

Methodology

The word "ethnographic" can be defined as "portrait of a people". Ethnographers participate in the daily lives of people for an extended period of time – watching, listening, asking questions and collecting data – in the natural setting or real world (Hammersley and Atkinson, 2007). As a methodology, it provides an effective means to learn about people by learning from people (Roper and Shapira, 2000). Interpretive ethnography was chosen to study the culture of the social support group for parents. Interpretive ethnography is philosophically grounded in the hermeneutic tradition of Gadamar (1975) and Ricoeur (1992). Hermeneutics explores the process of interpretation in human enterprises, maintaining that interpretation is the primary epistemological process (Gehart and Lyle, 2001). In this endeavour, the researcher was interested in the parents' descriptions of their world. Social support groups are characterised by their function, which can be emotional or informational. The culture of the group in this study functioned in both of these ways, and was characterised by a sense of belonging.

The setting and study sample

The study was conducted in the west of Ireland where the primary researcher attended a monthly parent support group meeting for a period of 7 months, during which the parents granted permission for the researcher to attend. The support group was peer-led and meetings were approximately 2 hours long. Participants signed a consent form prior to the interview. Each participant was given an information sheet providing an outline the study, details of the ethical procedure in relation to protecting anonymity and reassurance that they may withdraw from the study at any time should they wish to. The time frame was confined owing

to a limit imposed by the primary researcher to complete a higher education programme. The group comprised a total of 30 parents and, on average, each meeting would have 10 parents in attendance, a majority of whom were mothers.

Data collection

The following three methods were used to gather data:

- Participant observation of the group meetings.
- Semi-structured interviews.
- Completion of a reflective fieldwork journal.

Participant observation was used over the course of the 7 months and was recorded in field notes that included a topography of the setting. To supplement the descriptions of the culture that emerged from the field notes, group members were invited to participate in a semi-structured interview at a later stage.

Participants (n=8) for the interviews were approached by the researcher based on the principle adopted by Morse (1991) where key informants are sought on the judgement of the researcher, which is common in ethnographic approaches. This selection of participants relies on whom the researcher perceives to have experience and insight of the phenomenon, as well as the willingness to speak about it. This, in essence, was the eligibility criteria. The researcher did not want to restrict the sample to just parents coping with a "new" diagnosis but wanted a good representation of all types of experience. The interview length ranged from approximately 25 minutes to 1 hour and 8 minutes, and the interviews were semi-structured to encourage dialogue.

Ethics and reflexivity

Ethical approval was obtained from the local research ethics committee of the health service executive in Ireland. Informed consent, anonymity and confidentiality were maintained throughout the study. All names used in the findings are pseudonyms. Interpretive ethnography requires the researcher to acknowledge his or her influence on the research process and this was addressed by reflexivity, which is the process of self-awareness adopted and communicated by the researcher. This draws attention to the likely effects of personal views on the research results

and it enhances the quality of the research by extending the understanding of researchers in regard to how their positions affect all stages of the research process (Primeau, 2003). Speziale and Carpenter (2007) believe any nurse conducting ethnographic research must accept reflexivity as part of the research design. Reflexivity also enhances the credibility of qualitative research (Koch and Harrington, 1998). As participants of the study were aware that the primary researcher is a DSN, they often viewed her as a DSN, which, on occasion, created role conflict. For example, the parents looked for confirmation when discussing particular aspects of their child's care to which advice was offered. Conversely, the researcher often clarified her interpretation of her observations with the group members through casual conversation. Hand (2003) considers these instances as opportunities for reciprocity where the participants can gain from the encounter as well as the researcher. Negotiating the relationship with participants is a challenge as there is a risk of the researcher becoming too personally involved and losing objectivity. According to Hammersley and Atkinson (2007), there must always be some social and intellectual "distance", as it is in the "space" created by this distance that the analytical work is completed by the ethnographer. Allan (2006) has discussed the challenges in attempting to maintain an "outsider" relationship when one is both a researcher and a nurse. The primary researcher communicated these tensions in writing the field notes and addressed them in a reflexive manner by being attuned to the fact that there was an "assumed position of knowing" (Pellatt, 2003).

Data analysis

Each period of participant observation was followed by data analysis, which led to more focused fieldwork, as favoured by Spradley (1980). The themes and categories derived from the field-note observations provided a guide for the schedule of eight semi-structured interviews. The transcripts were returned to the participants for verification to ensure accurate representation of their respective statements (Twycross and Shields, 2005). The researcher applied the analytical framework by Gantley (1999) which offers structure to managing the data by identifying issues (low-level topics), categories (groups of issues) and analytical themes (theoretical perspectives linking the themes).

Literature review

In the literature, the advantages of social support group involvement have been described as feelings of being in the same "boat" and a belief that collective wisdom is borne via the shared experience of the participants (Davison et al, 2000; Leung and Arthur, 2004). Becoming a member of a group has implications for how people see themselves, which can assist them in normalising their identity. Making comparisons with other group members is a fundamental trait of the social psychological function of a support group and serves to ensure group participation. Social comparison theory (Festinger, 1954) proposes that comparison occurs between people and that affiliative behaviours increase as people seek the opinions of others about how they should be thinking or feeling (Davison et al, 2000). The experience of having a child diagnosed with type 1 diabetes has been described in the literature as traumatic and devastating, with emotional responses reported as feelings of shock, anger, denial, sadness, frustration, disbelief, guilt, blame, despair, sorrow and anxiety (Buckloh et al, 2008; Bowes et al, 2009).

Findings

Two themes were identified, specifically relating to the issue of social support and how this is described by the parents (see below).

The culture of the group: "A different kind of support"

The group setting was characterised as a place in which parents could learn how to cope from exchanging experiences with one another. This was evident in this study, as one participant said:

"It gave me the confidence to know that what I was feeling was normal and that I wasn't going mad. I would be so elated when I came home from a meeting, I wouldn't be able to sleep. I could say to my husband, 'I am not the only one… I cannot believe that someone else feels the way I do'. They all did." (Liz, son diagnosed at 13 years of age)

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Page points

1. Providing a setting for parents in similar situations to share their experiences appeared to alleviate a sense of loneliness and isolation.

2. Group membership was described as offering a sense of belonging, solidarity and equality, as well as a significant amount of emotional and social support.

3. The type of knowledge that is exchanged in support groups has been articulated as "experiential knowledge" and is distinct from that offered by healthcare professionals and lay people.

In the meetings, participants would actively listen to others with open body language giving each person time to tell their story, in which comparisons with the experiences of others appeared to have a strengthening and hopeful effect.

"The parent support group was fantastic and a 'lifesaver' for me because it got me out of myself. I could see other mothers coping and I said to myself 'I can do this'." (Eleanor, daughter diagnosed at 5 years of age)

The impact of hearing how others were coping seemed to be particularly powerful, as one participant stated:

"I thought I wasn't coping any better a year on from the diagnosis but I then realised I had moved on a lot when I saw how upset the other mothers were with children newly diagnosed. I was relieved and happier in myself I was doing better." (Mary, daughter diagnosed at 5 years of age)

Being with parents in the same situation appeared to alleviate a sense of loneliness and isolation, giving participants the space to express their feelings. Participants described the culture of the group in unique terms that fulfilled a need for them that they found was neglected in health care services:

"Meeting other parents in the group was fantastic, just that kind of support from others in the same boat. It is a different kind of support to that given by healthcare professionals." (Jane, son diagnosed at 6 years of age)

Similarly, another parent noted:

"'The diabetes nurse did say there would be huge grief and yet there was no emotional support. I got emotional support from the parent support group. They knew what I was going through." (Liz, son diagnosed at 13 years of age)

One parent described having the space to express emotions without fear of judgement:

"The parent support group was a 'lifesaver' for me because it was the only situation where I didn't feel guilty about saying I had a bad day because

they knew I wasn't moaning. They had days like that themselves." (Deirdre, daughter diagnosed at 5 years of age)

The context of the emotional support was also found to be important:

"You can share your frustrations and worries as it is a meeting of minds on an issue that nobody else understands. We all have the same grief and this is consoling for us." (Sarah, daughter diagnosed at 6 years of age)

The benefits of the group: "You are so lost in the beginning"

At the diagnosis stage, parents felt particularly overwhelmed and discussed their fears and doubts (Smaldone and Ritholz, 2011). Descriptions of these emotional responses were also prevalent in this study, as one participant stated:

"You are so lost in the beginning, so terrified and you don't know if you are doing the right thing. It is a fear of the unknown. Attending the group is hugely supportive… sanity saving in some respects." (Caroline, son diagnosed at 10 years of age)

Group membership is widely considered as offering a sense of belonging, solidarity and equality, as well as a significant amount of emotional and social support (Bowes et al, 2009). Being part of the group ensured that a network of support was available:

"Three months since the diagnosis, my daughter got really upset and hit a 'blank wall' of her own personal grief. When that hit her, I just gave in and said 'I am fed up pretending this is okay' and I was crying with her. I rang one of the parents in the support group three times that week" (Mary, daughter diagnosed at 5 years of age)

Another parent explained:

"One day, his blood sugars were really high and I couldn't get through to the hospital. I rang one of the parents in the parents support group. I thought she was fantastic. She helped me out so much that day." (Ann, son diagnosed at 7 years of age)

The context of emotional support is based on a sense of solidarity and sharing of experience. The

type of knowledge that is exchanged in support groups has been articulated as "experiential knowledge" (Borkman, 1997) and is distinct from that offered by professionals and lay people as its unique process of development appears to offer members both practical and emotional support.

Discussion

In this study, attending the social support group appeared to offer parents an environment to communicate the emotional aspects of parenting that they felt were lacking in conventional therapeutic settings, as concluded in other studies (Bowes et al, 2009; Edmonds-Myles et al, 2010). Parents seem to have accepted the notion that they are not encouraged to speak about their emotions at clinic time, which would suggest that the orientation of care requires a review. Parental distress has health implications for the parent(s), the child and the overall functioning of the family. Interventions focused on parental psychological distress have demonstrated significant improvements in parental stress and distress, child behaviour and family outcomes (Hoff et al, 2005; Sullivan-Bolyai et al, 2010; Whittemore et al, 2012).

Clinic visits are primarily focused on the biomedical aspects of care for children with diabetes and nursing input is usually confined by these parameters, focusing the work solely on clinical aspects of the condition, such as blood glucose monitoring. The authors conclude that psychosocial care should become a more integral part of diabetes nursing, on the basis that DSNs are in an ideal position to be able to proactively contribute to enhancing coping skills, through sensitive attention to emotional needs and encouraging parents to seek appropriate support.

Limitations

Despite the aforementioned findings of this study, the authors note that the conclusions are limited in terms of generalisability, in light of the descriptive nature of the methods used and the small sample size of one support group. It should also be noted that the majority of the sample comprised mothers and it is likely that fathers may have similar experiences but may express them in qualitatively different ways, warranting further investigation. ■

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"DSNs are in the most ideal position to be able to proactively contribute to enhancing coping skills, through sensitive attention to emotional needs and encouraging parents to seek appropriate support."