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Community-based psychosocial interventions improve psychosocial outcomes for children and adolescents with type 1 diabetes mellitus and their families: A systematic review; and, Community mental health nursing for children/adolescents with type 1 diabetes mellitus and their families

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Community-based psychosocial interventions improve psychosocial outcomes for children and adolescents with type 1 diabetes mellitus and their families: A systematic review

AND

Community mental health nursing for children/adolescents with type 1 diabetes mellitus and their families

Caris Bailey

A report submitted in Partial Fulfilment of the Requirements for the Award of Bachelor of Science (Occupational Therapy) (Honours), Faculty of Computing, Health and Science, Edith Cowan University.

Submitted (October, 2010)

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Community-based psychosocial interventions improve psychosocial outcomes for children
and adolescents with type 1 diabetes mellitus and their families: A systematic review

Caris Bailey

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Abstract

Background: Research indicates an increased prevalence of psychiatric morbidity in adolescents with type 1 diabetes mellitus in comparison to their peers. As a result, psychosocial community-based services are sometimes available to those who are experiencing psychosocial problems. Several reviews have examined the effectiveness of psychosocial interventions for children/ adolescents living with type 1 diabetes mellitus, however the psychosocial outcomes of psychosocial interventions being conducted in the community specifically, have yet to be systematically reviewed.

Objective: To systematically review the psychosocial outcomes of community-based psychosocial interventions for children and adolescents with type 1 diabetes mellitus and their families.

Subjects: Participants in the studies were limited to children or adolescents (0-18 years) with type 1 diabetes mellitus, as well as family members of a child/ adolescent with T1DM. Participants were included if they were receiving psychosocial services in the community.

Method: Electronic searches of four databases and manual searches of reference lists located relevant articles for this review. Articles which assessed the psychosocial outcomes of community-based psychosocial interventions used with children and adolescents with type 1 diabetes and their families were included. Data extraction and quality assessment was undertaken by two reviewers.

Results: Eleven articles were eligible for inclusion. Interventions included an internet coping skills training program, parent mentoring and peer support, in-home behavioural family

systems therapy, multisystemic therapy, motivational interviewing, and supportive telephone calls.

Conclusions: Various community-based psychosocial interventions produce differing psychosocial outcomes for individuals with type 1 diabetes mellitus and for their families. Interventions varied in efficacy in relation to improving psychosocial outcomes in this population. Methodological shortcomings included small samples or uneven study groups, and lack of blinding of the investigators and participants. There is a need for future research with more robust methodology in order to understand the outcomes of community-based psychosocial interventions for children/adolescents with type 1 diabetes mellitus and their families.

Key Words: Diabetes mellitus, type 1; adolescent; child; intervention studies; residence characteristics; psychology

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October, 2010

Abbreviations

BFST: Behavioural family systems therapy

ES: Effect size

MST: Multisystemic therapy

RCT: Randomised controlled trial

T1DM: Type 1 diabetes mellitus

Community-based psychosocial interventions improve psychosocial outcomes for children and adolescents with type 1 diabetes mellitus and their families: A systematic review

Introduction

Type 1 diabetes (T1DM) is one of the most common chronic diseases in children (1), affecting approximately 10,000 Australian children and adolescents (2). T1DM is typically diagnosed in individuals under 15 years, however can occur at any age, including the first year of life (1). Research indicates that the rate of T1DM has been increasing at 3.2% per year since 1990 (1) with 1825 Australians being diagnosed with the condition in 2006 (1). In Australia, the prevalence of T1DM in children is 17.8 per 100,000 (2).

Diabetes is one of Australia's most costly diseases (1). In Western Australia, the direct financial cost of diabetes in 2008 was approximately 1.2 billion dollars, of which, about a third was due to hospitalisations (3). There is an immense financial burden associated with T1DM on both a personal and government level; and despite people with T1DM comprising 10% of the diabetic population, they account for 42% of the overall cost of diabetes to Australia (1). As well as bearing the burden of living with diabetes, an individual with T1DM will incur substantial medical costs- between two and five times greater than a person living without diabetes (1).

Previous research has documented elevated rates of psychiatric disorder between 33-42% among adolescents and young adults with T1DM (4, 5), rates which are two to three times higher than those found in the general community (6). These findings are supported by results from a prospective longitudinal study (n=41) which found that one third of the adolescents with T1DM reported symptoms that met criterion for a DSM-IV diagnosis of a mood, anxiety, eating and/or behaviour disorder (7). This level of psychiatric morbidity is

approximately double that reported recently in Australian community samples based on either parent or self report (7).

Due to the increased prevalence of psychiatric morbidity in adolescents with T1DM compared to those in the general population (6), psychosocial community-based services are sometimes available to those who are experiencing psychosocial problems. Health care professionals that might be involved in providing such services include: community mental health nurses, psychologists, psychiatrists, general practitioners, occupational therapists, counsellors, and social workers (8). Examples of community-based psychosocial interventions include: home visits, group therapy, guidance, counselling, family therapy, cognitive behavioural therapy, other psychotherapies or psychosocial therapies, supportive psychotherapy, psychological skills training, mental/behavioural assessment and interpersonal psychotherapy (8).

Six systematic reviews have been identified that examined the effectiveness of psychosocial interventions for children and adolescents living with T1DM (9-14). However, the psychosocial outcomes of psychosocial interventions being conducted in the community specifically, have yet to be systematically reviewed. The objective of this systematic review was to explore the psychosocial outcomes of community-based psychosocial services for children and adolescents with T1DM.

Methods

The current review adopted the principles and techniques of systematic reviews in order to evaluate the literature and to locate relevant articles for inclusion (15). Electronic searches of Medline, the Cumulative Index of Nursing and Allied Health Literature (CINAHL), ISI Web of Science and PsycInfo were conducted. Each database was searched from January 2000 to June 2010. The main search terms were: type 1 diabetes mellitus, psychological or psychosocial outcomes, intervention and community. With the assistance of a librarian all terms were truncated, exploded and adjusted to match the specific database being searched. The search was limited to studies with samples of infants, children and adolescents. Reference lists of all relevant studies were manually searched.

A Priori criteria for inclusion of studies were applied first to locate abstracts and then to full text articles if the abstract did not provide adequate information. Studies were included if the psychosocial outcomes of an intervention were evaluated, if the intervention was psychosocial in nature, and if the intervention was conducted in the community (i.e. the participant's home, local park, local recreation centre, café etc.). The mode, length and frequency of interventions were not limited. Participants in the studies were limited to children or adolescents (0-18 years) with T1DM as well as family members of a child/adolescent with T1DM. Outcomes of interest included quality of life, family functioning, client satisfaction and mental health/psychological well-being.

Assessment of methodological quality

Two independent reviewers evaluated the methodological quality of each article using the assessment tool developed by Kmet, Lee and Cook (16). The second reviewer was blinded to authors. The assessment tool consisted of 14 questions and a scoring system (16). A methodological quality score was calculated for each article. The quality of articles were

classified as either strong (score >80%), good (score 70-80%), adequate (score 50-70%), or limited (score <50%) (17).

Data extraction

Two reviewers followed the guidelines detailed in Section 7 of *The Cochrane Handbook of Systematic Reviews of Interventions* (18) to extract relevant data from each study. Relevant data included: question/objective(s); study design; method of subject selection; characteristics of subjects; randomisation; blinding of investigators and/or participants; outcomes; sample size; analytic methods; estimate of variance; confounding controls; results and conclusions. Following data extraction, each study's level of evidence was determined using the National Health and Medical Research Council Guidelines (NHMRC) (19). Discrepancies between level of evidence or scores of each article were resolved through discussion.

Data synthesis and analysis

Due to insufficient data and lack of comparability among studies, a meta-analysis was not possible. A narrative review was undertaken in order to synthesise findings from the studies. Where sufficient data were provided, effect size was calculated (20), and were categorised as small (0.2 or less); moderate (0.5), or large (0.8 or more) (20).

Results

Electronic searches located 110 articles from Medline, 81 from CINAHL, 132 from ISI Web of Science, and 271 from PsycInfo for a total of 594 articles. Using the stated inclusion criteria, titles and abstracts were reviewed resulting in 60 potential articles (after accounting for duplicates). Full texts of the final 60 articles were reviewed for inclusion. Of the 60 articles, 11 met the inclusion criteria reporting on 9 different intervention protocols with a total of 641 participants. Excluded papers included viewpoints, editorials, case studies, opinions or conference proceedings and those not in English.

Articles meeting the inclusion/exclusion criteria ranged in publication date from July 2001 to June 2010. All studies investigated the psychosocial outcomes of a community-based psychosocial intervention for children/adolescents with T1DM, and/or for some or all of their family members.

Quality assessment of studies

The methodological quality of the included studies ranged from limited to strong (40.1%-89%) (See appendix A). Overall, consistent methodological weaknesses of the studies included small sample sizes, uneven study groups and lack of blinding of the investigators and participants. Some authors reported confidence intervals for the mean differences, none reported effect sizes. For the most part, measurement tools had sound psychometric properties and were appropriate to use with the specified population. The one exception is the Well-being Questionnaire, which was used to assess the mental well-being of children/adolescents with T1DM. The Well-being Questionnaire was used in two studies (21, 22), however it was designed to be used with adults with T1DM only (23). The National Health and Medical Research Council level of evidence table (19) was used to assign studies to one of four levels. Evidence from the highest level (level one) was obtained from

systematic reviews conducted with relevant randomised controlled trials (RCT); whilst evidence from level four included case studies and qualitative data (19). Eight studies included in this review are of level two evidence and three had level four evidence ratings.

Interventions

Interventions that were included were those that were community-based (usually the participant's home), psychosocial in nature, and used with children/adolescents with T1DM and/or their family members. One study assessed an internet coping skills training program (24); three intervention protocols assessed parent mentoring or parent social support programs (25-27); two articles assessed in home-BFST (28, 29); one article assessed multisystemic therapy (MST) as an intervention (30); two studies assessed motivational interviewing (21, 22); and two intervention protocols examined supportive telephone calls in youth with T1DM (31, 32). Intervention protocols ranged from five weeks to 15 months, and took place mostly in the participant's home; however some motivational interviewing sessions took place in a local park or cafe.

Outcomes

Four broad outcomes; quality of life, family functioning, client satisfaction and mental health/psychological well-being were evaluated (see appendix A). Changes in quality of life were evaluated in three of the 11 studies (22, 24, 31); measures included the Pediatric Quality of Life Inventory (33) and the Diabetes Quality of Life Measure for Youths (34). A randomised controlled trial (RCT) of motivational interviewing (22) found a significant increase in quality of life on the 'Satisfaction with life' subscale ($p<0.001$), the 'Impact of diabetes' subscale ($p=0.003$) and the 'Worries about diabetes' subscale ($p<0.001$) in the intervention group compared to the control using the Diabetes Quality of Life Measure for Youths (34). Calculations indicated that effect sizes ranged from moderate to large (0.7-1.34)

(see appendix A). At the 24 month follow-up, participants maintained improvements in satisfaction with life ($p=0.12$), perceived diabetes to have a less negative impact on their life ($p=0.008$), and continued to experience significantly less life worry ($p=0.001$). Due to insufficient data, effect sizes could not be calculated at the 24 month follow-up.

An internet coping skills program ($n=12$) (24) found those in the intervention group to report a better and clinically significant treatment quality of life ($p=0.20$) using the Pediatric Quality of Life Inventory (33); and a RCT examining the efficacy of supportive telephone calls ($n=46$) found individuals in the treatment group to report higher satisfaction with life at the three month assessment, however this was not sustained at six months.

Aspects of family functioning were assessed in eight (21, 22, 26-31) of the 11 articles. Many of the studies found the intervention to have no significant effect on family dynamics (21, 22, 26, 28, 29, 31); and studies used various outcome measures (see appendix A). A study piloting In-home Behavioural Family Systems Therapy (BFST) (29) observed positive changes in family functioning based on improvements in mother's scores on questionnaires. The mother's reported significantly less family conflict ($p=0.000$); less diabetes-related conflict ($p=0.002$) and less diabetes non-support within the family ($p=0.06$) post treatment, however these improvements were not maintained at the 6 month follow-up (28). In addition, multisystemic therapy resulted in significant improvements in secondary caregiver support (usually the father), in comparison to the control group ($p<0.05$) (30). However, the effect size was small (0.26). Finally, a study examining a parent mentoring intervention ($n=41$) (27), resulted in mothers perceiving their child's diabetes to have a significantly less negative impact on the family ($p=0.05$) in comparison to the control group, however the effect size was small (0.08).

Two studies assessed the participant's satisfaction with the intervention (24). Authors of the motivational interviewing for adolescents with diabetes pilot study ($n=22$) (21), asked participants to complete a post-intervention satisfaction questionnaire. Results from the questionnaire indicated 79% of those involved in the intervention rated the interviews as being helpful. Researchers involved in the development of an internet coping skills training program for teenagers with T1DM ($n=12$) (24), also assessed the participants satisfaction with the intervention using a satisfaction survey. Results obtained from the survey found that satisfaction with the internet intervention was high, and that those in the intervention group reported the program as being more enjoyable than the control group ($p=0.12$). Both questionnaires were developed by the authors.

Nine of the 11 studies assessed the participant's mental health/psychological well-being (21, 22, 24-29, 32). Outcome measures that were used can be seen in appendix A. Two of the 11 studies found the intervention to have no significant effect on the mental health/psychological well-being of the participants (26, 32).

Results from a pilot study of in-home BFST (29) observed improvements in the adolescent's psychological well-being based on the mother's reports on the Child Behaviour Checklist. The mothers reported statistically significant improvements in the 'internalising subscale' ($p=0.002$), 'externalising subscale' ($p=0.000$) and total Child Behaviour Checklist score ($p=0.024$). However, these improvements were not maintained at the six month follow-up (28), and authors suggest that this could be due to the insufficient length of the intervention (5-8 weeks).

A pilot study of motivational interviewing (21) found participants reported a significant reduction in fear of hypoglycaemia ($p=0.03$), and found diabetes significantly easier to live with ($p=0.03$) at six months. Following this, a RCT of motivational interviewing found the

intervention to have a positive impact on the intervention group in the areas of depression ($p=0.004$), anxiety ($p=0.001$), positive well-being ($p<0.001$) and total well-being ($p<0.001$) at 12 months (35). Effect sizes for these outcomes range from moderate to large (see appendix A).

Interventions also had a positive impact on the mental health/psychological well-being in parents of children/adolescents with T1DM. A social support intervention ($n=55$) (25) for mothers of children with a chronic illness, found that mothers of children with T1DM reported significantly less anxiety ($p=0.03$; ES 0.39). As well as this, a parent mentoring intervention (26) resulted in parents experiencing a significant reduction in diabetes-related concerns compared with the control group ($p=0.02$; ES 0.18).

Finally, an internet coping skills training program (24) resulted in adolescents with T1DM experiencing less perceived stress ($p=.20$), better coping ($p=.07$), better diabetes self-efficacy ($p=.20$), and an improvement in psychosocial adjustment.

Discussion

This systematic review found RCT and pre-experimental evidence to support the use of community-based psychosocial interventions to improve quality of life, family functioning, client satisfaction and mental health/psychological well-being in children/adolescents with T1DM and their families. Statistically significant improvements were found between intervention and control groups in a number of these studies. Effect sizes ranged from small to large, and no adverse effects were reported. However, the results must be interpreted with caution as the included research has many limitations, including small number of studies; small sample sizes; author groups and methodological quality. Studies for this review were located from only four databases, the literature was restricted to published articles, articles in English only, and studies undertaken prior to the year 2000 have not been reviewed.

Despite these limitations, eight of the 11 included studies provide level two evidence for psychosocial outcomes. In addition, measures indicated improvement or prevention of deterioration of psychosocial outcomes. Effect sizes varied, but all were positive (0-2.52).

The 11 studies included in this systematic review report the impact of psychosocial interventions on the quality of life, family functioning, client satisfaction and mental health/psychological well-being of children/adolescents with T1DM and their families. Many of the studies reported the intervention to have no significant impact on the psychosocial outcomes of the study participants (26, 28, 31, 32) whilst one reported small clinically significant changes (30). However, the lack of detection of a significant difference may be due to small sample sizes and insufficient intervention periods (24, 28, 29).

A few of the included studies highlighted the importance of transferring psychosocial treatments from the typical office environment to the context in which behaviours naturally occur (i.e. the participant's home) (29, 30). Psychosocial interventions taking place in the

home allowed the interventionist to take into account not only the individual with T1DM, but also the family, and to observe the environment in which the family lived (30). In addition, a few studies commented on the ease of modifying and implementing a once office-based service in the home (28, 29), as well as concluding that home-based psychosocial interventions were more cost-effective (27, 29) in comparison to standard care. Further clinical implications of the research include that because the interventions were home/community-based, families have been found to more actively participate in treatment (28). The authors concluded that this may have been due to the service being delivered in a more convenient manner (28).

Many studies have concluded that there is an ongoing need for the development, implementation, and evaluation of evidence-based psychosocial treatments for adolescents with diabetes who have failed to respond to traditional psychosocial and medical treatments (22, 27-31). It is still not clear how community-based psychosocial interventions impact on the psychosocial outcomes in children/adolescents with T1DM and their families, and this may be due to the individual nature of adolescents' response to interventions. Future research should employ a mixed-method approach to further understand the impact a community-based psychosocial intervention has on children/adolescents with T1DM and their families. Using a mixed methods approach would allow the researcher to explore and describe the experiences of children/adolescents receiving the psychosocial intervention, and would be beneficial as it would enable triangulation of the findings (36).

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Guidelines for contributions by authors

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Community mental health nursing for children/adolescents with type 1 diabetes mellitus and
their families

Caris Bailey

Abstract

Background: Research indicates that children/adolescents with type 1 diabetes mellitus experience increased mental health issues in comparison to those in the general population. In response to this, a community mental health nurse working for the Department of Endocrinology at Princess Margaret Hospital for Children, Western Australia, provides a psychosocial service for families in which there is a child with type 1 diabetes mellitus, and who are experiencing mental health difficulties.

Objective: To explore the experience of type 1 diabetes mellitus for children/adolescents and their families; and to describe and explore the role of the community mental health nurse for children/adolescents with type 1 diabetes mellitus and for their families.

Subjects: Study participants were parents or caregivers of children/adolescents with type 1 diabetes mellitus, as well as their children with type 1 diabetes mellitus who were 12 years of age or older. Participants were recruited from the Department of Endocrinology at Princess Margaret Hospital and were invited to partake in the study if they had seen the community mental health nurse at least five times in the previous 12 months.

Method: Mixed methods design. Two males (aged 15), two females (aged 13 and 16), and one or both of their parents participated in semi-structured interviews, and completed a battery of questionnaires. In families where children were less than 12 years of age, only the parent(s) were assessed.

Results: Analysis of interviews revealed that the main themes were: type 1 diabetes mellitus has a significant emotional impact on the child, as well as their parents; type 1 diabetes mellitus has a major impact on the lifestyle of children living with the condition and their parents; and the community mental health nurse has a positive impact on families receiving the service.

Conclusion: Community mental health nursing is a well-received intervention, which has shown to have a positive impact on the lives of children with type 1 diabetes mellitus and their families, who are experiencing mental health issues. Further research should be carried out on a larger sample and using a more robust methodology.

Key Words: Diabetes mellitus, type 1; adolescent; child; residence characteristics; psychology; nursing

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Abbreviations

CBCL: Child Behaviour Checklist

CMHN: Community mental health nurse

FAD: Family Assessment Device

MDT: Multi-disciplinary team

PMH: Princess Margaret Hospital

T1DM: Type 1 diabetes mellitus

Introduction

Type 1 diabetes mellitus (T1DM) is a chronic, life-threatening condition which is characterised by a total lack of insulin, an elevation in blood glucose levels, and a breakdown of body fats and proteins (1). In an individual with T1DM, the body is unable to manufacture insulin as their immune system produces islet cell antibodies, which destroy the pancreatic beta cells responsible for insulin production (2). T1DM is one of the most common chronic childhood disorders (3), affecting approximately 10,000 Australian children and adolescents (4). T1DM permeates the lives of children and their parents (5), and research indicates the prevalence has been increasing at 3.2% per year since 1990 (3). In order to survive and avoid diabetic complications, individuals with T1DM must take numerous insulin injections or receive insulin through a pump daily for the rest of their lives (3).

Diabetes is one of Australia's most costly diseases (3). In Western Australia, the direct financial cost of diabetes in 2008 was approximately 1.2 billion dollars, of which, about a third is due to hospitalisations (6). There is an immense financial burden associated with T1DM on both a personal and government level, and despite people with T1DM comprising 10% of the diabetic population, they account for 42% of the overall cost of diabetes to Australia (3). As well as bearing the burden of living with diabetes, an individual with T1DM will incur substantial medical costs- between two and five times greater than a person living without diabetes (3).

Recent research has documented elevated rates of psychiatric disorder between 33-42% among adolescents and young adults with T1DM (7, 8), rates which are two to three times higher than those found in the general community (9). These findings are supported by results from a prospective longitudinal study (n=41) which found that one third of the adolescents

with T1DM reported symptoms that met criterion for a DSM-IV diagnosis of a mood, anxiety, eating and/or behaviour disorder (10).

Due to the increased prevalence of psychiatric morbidity in adolescents with T1DM compared to those in the general population (9), psychosocial community-based services are sometimes available to those who are experiencing psychosocial problems. Health care professionals that might be involved in providing such services include: community mental health nurses, psychologists, psychiatrists, general practitioners, occupational therapists, counsellors, and social workers (11). Examples of community-based psychosocial interventions include: home visits, group therapy, guidance, counselling, family therapy, cognitive behavioural therapy, other psychotherapies or psychosocial therapies, supportive psychotherapy, psychological skills training, mental/behavioural assessment and interpersonal psychotherapy (11). The over-arching aim of these therapies is to meet the emotional needs of the individual that are often over-looked by the medical team; and are often conducted face-to-face, via telephone, video link, or through other forms of direct communication (11).

Research relating to childhood diabetes is extensive, however is primarily quantitative. A search of the literature identified six qualitative studies exploring the experience of T1DM for children/adolescents and their families (12-17); however, failed to identify any qualitative research study that examined the role of a community mental health nurse (CMHN) for young people living with T1DM and their families. Several studies explored the effectiveness of community-based psychosocial interventions for children with T1DM, however they use a quantitative approach, are mainly questionnaire based, and none of the interventions have been administered by a CMHN (18-28). Whilst these studies contribute to knowledge of the

impact of community-based psychosocial services on a child with T1DM and their families, a gap in the research remains. The objectives of this study were: To explore the experience of type 1 diabetes mellitus for children/adolescents and their families; and to describe and explore the role of the community mental health nurse for children/adolescents with type 1 diabetes mellitus and for their families.

Methods

Because the individual experiences of those receiving services from the CMHN were of interest, and given the paucity of research in this area, a mixed methods approach was used. Mixed methods research allows the researcher to address the limitations of qualitative and quantitative approaches (29), and can increase the validity of the findings (30). The qualitative component comprised of semi-structured interviews with the participants, and the quantitative component, the administration of questionnaires.

Participants

A purposive sample was recruited through the Department of Endocrinology at Princess Margaret Hospital for Children (PMH), Western Australia. Study participants were parents or caregivers of children/adolescents with T1DM, as well as children with T1DM who were 12 years of age or older. Parents or caregivers of a child/adolescent with T1DM who had received more than five visits from the CMHN in the previous year were contacted. Families were excluded from the study if they were unable to give consent, or if their consultant deemed it inappropriate for them to participate in the study (i.e. if the family was in crisis, or due to safety issues). Eight families met the inclusion criteria, and all eligible families were sent a letter of invitation to participate from their consultant.

Ethics and consent

The research protocol was approved by the Edith Cowan University Human Research Ethics Committee and the Princess Margaret Hospital for Children Research Ethics Committee. Informed consent was obtained from all participants. Parents and children were provided with separate and specific written information about the study, and had the opportunity to ask

questions before making the decision to participate. Confidentiality and anonymity were assured and pseudonyms are used in the presentation of all data.

Data collection

Qualitative

Two semi-structured interview guides (one for use with the parent(s), and one for use with the child/adolescent) (see appendix B) were developed by the researcher, and were altered following feedback and suggestions from clinical experts. Following this, the guides were piloted with a mother and child who met the majority of the study inclusion criteria. Families were sent a letter of invitation to participate in the study, and were then contacted by telephone and asked if they and their child (if over 12 years of age) would be interested in taking part in a semi-structured interview exploring their experience of living with T1DM, as well as their views on the CMHN. All semi-structured interviews were conducted in the families' homes, as it enabled a comfortable and convenient environment for disclosing potentially personal information. Children and their parent(s) were interviewed independently, allowing each participant space to talk freely about their experiences without feeling constrained by their parent or child. Prior to each interview, the researcher explained the study, and gained consent from each participant. Each interview was audio-recorded with participants' agreement and transcribed verbatim.

Quantitative

The quantitative component of the study comprised of the parent(s)/caregiver(s) and children over 12 years of age completing a number of questionnaires used to obtain information on demographics, family functioning, psychological adjustment, quality of life and client satisfaction. Prior to data collection, the questionnaires were piloted with a mother of a child

with T1DM, who completed all the questionnaires and confirmed the questions were appropriate and suitable.

Demographics: A non standardised questionnaire comprised of 14 questions was used to obtain information relating to age, sex, ethnicity, marital status etc. (31). Two demographic questionnaires were completed by parents/caregivers of the children. One parent demographic questionnaire was answered according to the parent(s) characteristics (31), and the second was answered on behalf of their child. The demographic questionnaire developed for use with the child was based on the parent demographic questionnaire (31), but was slightly altered by the primary researcher, so that all questions were relevant to a child.

Family functioning: The 12-item General Functioning Scale (GF) of the Family Assessment Device (FAD) is a shorter version of the FAD, and was used to obtain a measure of overall health/pathology of the family (32). The GF subscale of the FAD has an internal consistency of 0.86 (Chronbach's alpha), and has been found to be a valid measure of family functioning (32). The GF subscale of the FAD was completed by participants 12 years of age or older who rated the questions based on their perception of how their family functions.

Psychological adjustment: The Child Behaviour Checklist for ages 6 to 18 (CBCL/6-18) and Youth Self Report (YSR) was used to measure the child's problem behaviours and competencies. Children over 12 years of age rated themselves using the self-report form, and the parent(s)/caregivers scored the checklist according to how they perceive their child. The questionnaire has strong test-retest reliability (0.95-1.00), inter-rater reliability (0.93-0.96), internal consistency (0.78-0.97), and is valid (33). The CBCL was scored by an experienced psychologist, and although the CBCL produces an array of subscale scores, only the 'externalising behaviours' score was used for the purposes of this study.

Quality of life: The Diabetes Quality of Life for Youth Measure was used to assess the quality of life of adolescents with diabetes (34). The questionnaire contains 52 items which

comprise of four subscales: Impact of diabetes, worries about diabetes, satisfaction with treatment, satisfaction with life, plus one single item on health perception (35). Reliability of the satisfaction subscale is 0.85; impact: 0.83; and worries: 0.82 (35). The Diabetes Quality of Life for Youth Questionnaire was completed by children 12 years of age or over, and was also completed by the parent(s)/guardian who answered the questions on behalf of their child.

Client satisfaction: The Client Satisfaction Questionnaire-8 was used to assess the participant's overall satisfaction with the service they receive from the CMHN from PMH (36). The CSQ-8 is an eight item, easily scored and administered measurement, that has an internal consistency of 0.93, high concurrent validity (37) and construct validity (36). The Client Satisfaction Questionnaire-8 was completed by participants 12 years of age or older.

Questionnaires were rated by the participants following completion of the semi-structured interview. A research assistant was present whilst participants filled in the questionnaires to answer any queries regarding specific questions.

Data analysis

Qualitative

All interviews were transcribed verbatim and compared with field notes. The open coding method (38) was used to name and categorise data. Significant statements were identified by the researcher and coded. Constant comparative analysis was used (39), whereby new codes were compared with those that had emerged from previous interviews through a process of moving back and forth between transcripts. Codes were then classified into broader categories that emerged to form major themes (40).

Quantitative

The General Functioning subscale, Diabetes Quality of Life for Youth Measure and Client Satisfaction Questionnaire-8 were scored and interpreted by the primary researcher, as per assessment manual instructions. The CBCL was scored by an experienced clinical psychologist. Questionnaire data was used for descriptive purposes only. For assessment results, see appendix C.

Maintaining rigour

Credibility, dependability, transferability and confirmability are strategies for addressing the issue of rigour in qualitative studies (41). Dependability and confirmability in this study was achieved through careful planning, maintaining an audit trail, using stable instruments attention to detail, and consulting professionals at all stages of the study. Transferability was established through the detailed description of the sample and research context (42). In addition, audio-recording and verbatim transcription of the interviews allowed accurate analysis and interpretation, and enabled the researcher to use quotations which assist in establishing the trustworthiness of the study. A research journal was also kept by the first author which recorded reflections on interviews (43). After themes had been depicted from the interviews, member checks were conducted with 3 families to further enhance the credibility of the study.

Results

Participant characteristics

All eight families that were contacted agreed to participate in the study, however one family was unable to be interviewed due to a crisis, and one family agreed, but was then too busy. Subsequently, a total of 6 families (4 children with T1DM, 2 fathers and 5 mothers) participated in semi-structured interviews. The children who participated were: Megan (aged 13); Clinton (aged 15); Josh (aged 15); and Rachel (aged 16). Two children were ineligible for participation in the study, as one child was too young (aged 11 years), and one child (aged 16) had not seen the CMHN in the previous 12 months, and was no longer living with his parents. The mean age of the parents was 44.2 years (range 35-51; median 46 years). Five parents were born in Australia, one was born in Poland, and one was born in Croatia. Three parents were married, two were living with a partner, one was divorced and one was separated. All parents resided in a private residence; three parents worked full-time, one worked part-time, two were home-makers, and one was unemployed. Five of seven parents received a Carers allowance. Three children were born in Australia, and one was born in the United States of America.

Qualitative

Three common themes emerged from the interviews: the emotional impact of T1DM; the impact of T1DM on lifestyle; and the positive impact of the community mental health nurse on their lives, were common to the children's and parents' data (see appendix D).

Theme one: The emotional impact of T1DM

Many of the participants expressed how living with T1DM had significantly impacted on their emotional well-being. Parents, as well as their children all indicated that adjusting to the

diagnosis of diabetes, as well as the perception of being "*different*" from their peers had a negative impact on them emotionally. In addition, all parents described feeling a significant amount of parental worry in relation to the management of their child's diabetes. Many described substantial changes in their child's mood, as well as their own mood, following the diagnosis.

Dealing with the diagnosis.

When a child is diagnosed with T1DM, it not only affects the child but the entire family.

One mother explained that when her son was diagnosed at nine years of age, it was dealing with emotional aspect of living with diabetes, rather than the physical aspect that she found difficult:

"It was more the emotional aspect...I don't think my husband realised how it was affecting me emotionally, and the stresses and the wear and tear and that sort of stuff. He thought I was handling it, and so I said to him 'but I'm not really handling it, I mean, I might look like I am, but I'm not', it was all a front really".

Another parent explained that when her daughter was first diagnosed with T1DM, she felt hopeless, became depressed, and started to blame herself for her daughter acquiring the condition:

"It was hard, because I kept asking the question 'why?' Because we didn't have anybody in the family with it, and then I blamed myself".

Lowes (2008) supports this by explaining that when a child is diagnosed with T1DM, the parents generally experience a range of emotions, such as shock, guilt and anxiety (44). In addition to this, Lowes (2008) continues to discuss how very often health professionals tend to focus solely on the practicalities of diabetes management, while the emotional needs of families can be over-looked (44).

Being 'different'.

Adolescence is a period in which individuals wanting to be the same as their peers is typically of high priority (45). Both parents and children who were interviewed explained that being diagnosed with T1DM resulted in them having to carry out tasks that are different to that of their peers. Josh (aged 15) explained how having to carry out diabetes-related tasks interfered with his socialising at school:

"Every day at school I have to take five minutes out of my lunch just to do the needles and stuff, and so I miss out on just hanging out with friends and stuff".

Another child, Megan (aged 13) discussed how her parents and doctors felt that as she was getting older, she should begin to start injecting insulin at school:

"They wanted me to start doing injections around lunch time, but I didn't want to... I didn't want to do it in front of everyone".

Megan went on to explain that although her peers and teachers at her school were aware of her diabetes, she would still rather administer her injections at home, as she preferred to enjoy a "normal lunch-time" spent playing with her friends.

Parents of the children also observed their child's desire to be normal. One mother explained how her son often chose to ignore his condition, in attempt to be like his friends:

"He's got himself into a bit of vicious cycle, where he's like 'If I don't do a needle, I'm not a diabetic' but then it makes him sick, and makes him realise 'I have diabetes' even more".

Another mother described the burden that T1DM placed on her daughter, and the impact it had on her ability to perceive herself as "normal":

"She's like any adolescent, she doesn't want to be different, and so there's less and less monitoring of her sugar levels and less injections. If she goes to sleep-over's she won't do it [injections] because she thinks she will be fine".

Parental anxiety.

Many of the parents explained that the original diagnosis was a difficult period in both their and their child's life, and even years following the diagnosis, they continued to feel considerable parental worry and anxiety in relation to diabetes. One mother articulated this:

"It seems since his diagnosis that I can't relax much, and that I'm always worried, stressed and like: 'Is he going to be okay?'"

Another mother said:

"There's never a day that goes by that I don't think: 'Is she alright?' 'Has she eaten properly?' 'Has she done her injections?' 'What are her levels like?' You know, you never stop thinking about it. It's a constant worry in the back of your mind".

Research supports this, by explaining how the most common overriding parental fear often concerns hypoglycaemia; and parental anxiety is often heightened when their child is not with them, as parents must rely on others to recognise what is happening, or know how to treat the change in sugar level (44).

Changes in mood.

Every parent in the current study explained that following being diagnosed with T1DM, they observed dramatic changes their child's mood. Rachel (aged 16) explained that many fights with her mother stemmed from her being in a bad mood, and she had begun to recognise that her mood was strongly associated with her blood sugar levels:

"When I'm in a bad mood I'll go check my levels... and the majority of the time that is the reason why..I get really angry for no reason, I just get really frustrated".

Josh (aged 15) also explained the impact of T1DM on his mood:

"If I'm low I'll be shaky and not really as responsive and get annoyed a lot easier. Same if I'm high, I'll get annoyed really easily and probably not respond as well as I do when I'm at normal reading".

Literature has documented that as children transition into adolescence, they become increasingly aware that diabetes is for life, and this may result in changes in mood, expressions of anger, frustration and sadness (44). It should be noted however, that many studies have found children with chronic illnesses are as emotionally healthy as their peers (44).

In addition to changes in the child's mood, parents described changes in their own moods. Rachel's mother explained the sadness she feels about her daughter being burdened with the condition:

"No parent wants their child to have to go through this- the constant management and control, and the lack of spontaneity in life and having to watch what you eat, what you do, and where you go, and make sure you've got packed food and all that kind of stuff...it's sad".

This finding supports research by Bowes (2008), who found parents of children with T1DM often feel sad on a daily basis, as they watch their child injecting, blood glucose monitoring, or avoiding sugary treats (46).

Theme two: Impact on lifestyle

Every family noted significant changes in their lifestyle as a result of being diagnosed with T1DM. Areas of life which appeared to have been impacted most substantially were the way in which the family functioned, the child's diet, and the child's school attendance and performance.

Family functioning.

Many of the participants discussed how living with T1DM impacted on their family. Parents in particular noted that since their child's diagnosis with T1DM, that child had received extra attention and care in comparison to their siblings which had contributed to conflict between

family members. Vicki described how since her son was diagnosed he had been treated differently to his sisters:

"I've let Clinton get away with things I've never let the girls get away with, or do and that's partly because he's diabetic now. Normally, it's, 'You do as we say', and that's it. So that's how it's been different. The girls will say, 'Why does he get to do that? I never got to do that. Why is he doing that?'"

Martha also spoke of how her son Daniel (aged 11) received more care and attention in comparison to his step-brother, despite her best efforts to provide equal care:

"His brother became very jealous of Daniel because Daniel was diabetic and got that extra little bit of care, but we tried to level it out and do the same to him but, yeah, it didn't work out so he ended up moving out [of home]".

Rachel (aged 16) described how her diabetes had impacted on her family. She explained how she perceived her mother to be very controlling and spoke of how her mother would "nag her" about her diabetes control, which would most often result in arguments:

"Diabetes would start lots of the fights because she would ask me, 'Have you done your injection?' and then I'd just snap and start to fight, and bring up other things and stuff like that".

Diet.

After being diagnosed with T1DM, the most obvious change in lifestyle recognised by the participants was the change in diet. All of the children and adolescents explained how adhering to a healthy diet, counting carbohydrates, and determining how much insulin was required was a "huge issue" for them. Megan (aged 13) explained how she struggled with not eating sugary foods, and how this struggle had magnified since starting her first job in a food store. Megan described how she and her mother would fight about what she could and could not eat:

“When I buy chocolate she gets really angry at me and takes it away so I can’t eat it. She’ll let me have it if my sugars are good”.

Rachel (aged 16) also described how she found it hard adhering to a healthy diet, and explained how it often affected her family when she was younger:

“When I was little mum used to love having Redskins and she’d have to hide them. So she’d feel really bad and I’d always get angry at her and be like, ‘Why did you bring lollies home? Cause I can’t have them!’”

Martha also explained the difficulty her son experienced with change to his diet:

“You know, he went from having Milo bars to take to school to nothing like that...and he still says stuff like, ‘Oh mum, I’d love a doughnut!’ And like, ‘Can I just have a little bit?’ and then he talked us into getting him a chocolate sundae the other week and I said, ‘That’s it now you can’t have anything else for the rest of the week!’”

Martha also highlighted how she felt she had to compensate her son for his good eating habits, and how difficult it was for him to see children at school eating foods he could not have:

“He see’s kids eat chocolates and all that, so what we try and do is compensate for it like if other kids are getting chocolates or whatever, we’ll then say, ‘Okay um what about if we go to Time Zone?’ And every now and then, ‘Would you like a new Xbox game?’ or, ‘Do you want a toy?’ You know, instead of giving him sweets”.

School.

Many parents reported their son or daughter as having difficulty with school attendance. Poor school attendance was described as a result of fatigue, and being unable to get out of bed in the morning. Josh’s (aged 15) father explained that his son had great difficulty with attending school and that he was sure he would attend more if he did not have T1DM:

“I think to myself, ‘If he didn’t have this illness would it be different?’ I think to myself, ‘It would be different, he would just go to school every day and he would do what he had to do!’”.

Another mother explained how her daughter's poor school attendance was often a result of her extreme fatigue, resulting from her consistently high blood sugar levels:

"It is a problem getting her to school in the morning... because she just can't get up...she's always high (blood sugar) and so she's tired".

In addition to poor school attendance, many of the parents explained that their child- and their child's school teachers- would often comment that their academic performance was often weakened as a result of their fluctuating sugar levels. One mother explained how her son Clinton (aged 15) would often be unable to recall what he had been taught during class due to low blood sugar levels:

"Some days he might have a hypo in class and then he will come home and say to me, 'I had a hypo during class, and I fixed myself, but I can't tell you what we learnt'".

Another mother explained how she would often discuss with the teachers how her son (aged 11) performed in class:

"There are times when the teacher says to me, 'He was quite alert today' and other times when she says he's been flat, 'He's been very flat'. So that's been on and off".

Theme three: Positive impact of the CMHN

The primary purpose of this study was to understand how the CMHN impacted on the lives of young people living with T1DM and their families. Each of the families was referred to the CMHN due to psychosocial difficulties. Participants indicated that the CMHN had helped specifically with providing reassurance; by being an independent person entering the family; by providing a personal and convenient service; by assisting in improving communication within the family; and by helping improve school attendance.

Reassurance.

Many of the families interviewed, explained that the CMHN helped them feel better, validated their feelings, and provided reassurance. In many cases, one parent appeared more

responsible for assisting in diabetes management than the other. As a result of this, the primary care givers often explained how worried they felt when left to manage the diabetes on their own, and how they often felt they were doing an inadequate job when their son or daughter's diabetes control was poor. Each parent interviewed felt that the CMHN has helped them to share their feelings, and provided reassurance that they were *going to cope and were doing a good job*. As explained by one mother:

"I think when talking to the CMHN, you just get that reassurance- that you're not the only one, and it's okay to have those feelings, and it's not the end of the world- although it used to feel like it every day...even if he [CMHN] just comes, sits down and listens to me, and says, 'That's okay', It does make me feel better".

Another mother explained that simply having someone to call at any time was very important and reassured her:

"The reassurance was good... just feeling that I can ring him at any time when I'm not coping is good".

These findings are supported by a study conducted in 2004, that noted it is important that parents of children with T1DM are made aware that their feelings are not abnormal, and that they may need to be given "*permission*" to grieve (47).

Independent person.

In addition to having someone to provide reassurance, all participants indicated that having a person coming into the home that was not going to "*take sides*", and made no judgements was a particularly advantageous aspect of the CMHN. Parents also acknowledged that they understand their children sometimes would often rather confide in someone other than their parents. Rachel's mother explained how having outside help was very beneficial for her daughter:

"There were a lot of dramas in her life and I knew that she needed some outside help. By having him [CMHN] come along in his capacity as a nurse but also as someone who

understands the mental health side of things... he was able to focus her on why she was feeling so angry...and she was able to confide in him. [As well as this], he wasn't on anyone's side and that was great for Rachel to see- that he wasn't taking sides, it's very important to gain their trust".

Another mother explained how important having someone in addition to herself was good for her son:

"There are things that Daniel will discuss with [the CMHN] that he doesn't discuss with me, but that's good, he's got someone there".

All of the four children interviewed felt that it was beneficial to have the CMHN as someone to talk to, and confide in. As Josh (aged 15) explained:

"When I had [the CMHN] come around, I knew I had someone to talk to. If I had problems with school, friends or parents, I had someone else to talk to".

Megan (aged 13) also described the benefits of having the CMHN come to visit:

"Having him [the CMHN] come felt good because he agreed with me, but he also agreed with mum".

Personalised.

All of the participants described feeling that the service they received from the CMHN was very personalised, and differed from the standard medical care provided at the hospital in that regard. As Josh's (aged 15) mother described:

"His sessions are very one-on-one and more personal- he knows you, he comes to your house, you don't see someone different every time and have to explain the situation over and over. Also, when you get to know someone like we got to know him- we actually felt comfortable with him and could talk to him".

Megan's (aged 13) mother further explained the benefits of having someone personable to confide in, and highlighted the positive way in which the CMHN worked:

“He was really friendly, nice and listened lots, and he didn’t try to give you advice like, ‘You should do this’, But rather, ‘what could you have done different?’ which was nice”.

Convenience.

The convenient way in which the CMHN service was delivered was one of the most discussed aspects of the service. Every participant noted the advantages of receiving the service in the comfort and privacy of their own homes. The parents of the children in particular appreciated the way in which the CMHN visited them at home, which resulted in less stress and more relaxation. Clinton’s (aged 15) mother explained why she felt this method of service delivery was of particular benefit to her:

“For him to come to my house, for me that is a big advantage because for me to go to Princess Margaret, even for clinic, um it’s a whole day you know?... So, the fact that he comes to the house, it’s brilliant”.

Rachel’s (aged 16) mother shared a similar view:

“Instead of us having to go to him, it was great for him to come here. It took a lot of stress off...having to bundle everything up, get in the car and go off, and then you feel like you’re being interviewed. Whereas when someone comes into your home, you’re more relaxed, and more ready to just chat, or cry or whatever”.

Josh’s (aged 15) mother explained that she particularly liked the way in which the CMHN worked around her busy schedule, and really appreciated the way in which the CMHN came to her home- as she is not able to drive. Clinton’s (aged 15) mother also highlighted the benefits of the service being provided in her home:

“I think it makes me more comfortable and relaxed... if I had to go and visit him, I would be so anxious about it, I don’t think I’d get the benefit out of it that I would at home”.

A study conducted in 2005 which reported on the efficacy of in-home family therapy for adolescents with poorly controlled diabetes and their families, supports interventions being conducted in the consumer’s home. The authors stated that despite the chaotic nature of the

families, and the high demand on their time, when services are offered in the home in a more convenient manner (i.e., the home) nonparticipation is attenuated (24).

Communication within the family.

When asked how the CMHN impacted on the family, many explained that he helped members with improving their communication. Rachel's mother explained how through employing communication strategies, the CMHN helped her and her daughter to listen, and understand one another:

"He was great because he would let me say things and Rachel would have to listen because otherwise we wouldn't talk. Yeah, we'd have to listen to each other and it was very revealing, it was really good because we learnt a lot about each other".

Rachel (age 16) also identified that the services received from the CMHN improved communication between her and her mother:

"He heard my side of the story and then he also heard mums side as well... and you didn't feel like you were the one that was wrong all the time... it was kind of the only way we could chat to each other without getting angry and it resulting in a fight".

Liaising with school.

As mentioned previously, poor school attendance was an issue for many of the families in this study. In some cases, the CMHN went to the school, and liaised with the teachers and other key parties in order to form school-attendance plans. Josh (aged 15) explained how the CMHN worked with him, his family, and the school to develop a graded return to school plan whereby he would increase his attendance gradually, and as a result was able to pass year nine:

"We put together a plan that I would go say, two periods then at recess I'd go home for that week, and then the next week I'd go three periods and then go home, and then next week- four periods and then keep going... he helped me get from year nine to ten".

Josh highlighted the instrumental support from the CMHN, explaining that he (the CMHN) even drove him to school on some days in order to make it easier for him and his family.

More service required

When asked how the service provided by the CMHN could be improved or altered, each parent indicated a desire for the service to be made more available in times of crisis, and when time was limited. Clinton's mother described this:

"It would be good if we had more of him... sometimes I have really wished he could just come to my house, and help me deal with my problems now! So a couple of him would be good... or an emergency one, something like that".

In response to the same question, children with T1DM said they were *"very happy"* with the service, and none reported any improvements or changes that could be made to the CMHN service.

Quantitative

Results from the questionnaires support the qualitative findings.

Family functioning: Results from the General Functioning subscale of the McMaster Family Assessment Device found that participants generally feel their family functions effectively. Scores ranged from 1.1-2.8 (see appendix C). These scores may be a result of the CMHN working with these families to improve their communication and general functioning; however further research using a pre-test post-test design would be needed to describe the impact of the CMHN on family functioning.

Psychological adjustment: 'Externalising behaviour' *t* scores from the CBCL ranged from 53-82 (see appendix C), indicating that some of the children experience rule-breaking behaviour, or aggressive behaviour problems. Two out of the four children scored in the normal range, one child scored in the clinical borderline range, and one child scored in the clinical range.

Four of the seven parents rated their child as being in the normal range, whilst three parents rated their child as being in the clinical range. One of the sub-themes that emerged from the semi-structured interviews was that children found their mood changed frequently, usually as a result of their fluctuating blood sugar levels. This is partially supported by the quantitative findings. On the YSR (ages 11-18) of the CBCL, all four children reported that their mood or feelings change suddenly as 'somewhat true'. On the CBCL (ages 6-18) in response to the same question, two parents reported that their child's mood or feelings change suddenly as 'very true'; two parents said this was 'somewhat true'; and two parents said this was 'not true' of their child.

Quality of life: Results from the Diabetes Quality of Life for Youth Questionnaire support qualitative findings that indicate diabetes has a substantial impact on the lives of children/adolescents, and that children/adolescents experience various worries associated with diabetes (see appendix C). For the 'impact of diabetes' subscale, scores ranged from 41-83, indicating that diabetes impacts the lives of these children. However the degree of impact diabetes had on children varied. In addition, the 'worry about diabetes' subscale, supports that those participating in the study had worries associated with diabetes. Scores for this subscale ranged from 15-55. Higher scores indicated greater impact/ worry.

Client satisfaction: Scores from the Client Satisfaction Questionnaire-8 (see appendix C), ranged from 22-32, indicating that participants were highly satisfied with the service they received from the CMHN. This finding is validated by the qualitative results, which found there was a high level of satisfaction with the service provided by the CMHN.

Discussion

Overall, this study explored the experience of T1DM for children/adolescents and their families; as well as the important role the CMHN played in helping these families. This primarily qualitative study was the first to explore and describe the impact a CMHN has on families who have a child with T1DM.

Limitations and further research

This study was limited by the small sample size, and saturation was not reached. Further limitations include that the quantitative data was used for descriptive purposes only; and children under the age of 12 years were not interviewed. Due to the age restriction, one child (aged 11) was ineligible for participation, and therefore an important opinion has not been included in this study. This study and its design has allowed for exploration of the experiences of individuals living with T1DM, and their perception of the community mental health nurse service. Further research, employing more rigorous experimental methodologies would enable a measure of the efficacy of this service. In addition, longitudinal research would enable an understanding of how the community mental health nurse impacts on children/adolescents and their families with T1DM over time.

Clinical implications

This study highlighted the importance of health professionals providing services in the community. Results from this study indicate that the CMHN service is very well-received by its consumers, and that a lot of important work is being done with families that are experiencing emotional and lifestyle difficulties as a result of the pressures associated with living with T1DM. Results indicate that these families have multiple and complex needs, and that they highly value services being conducted in their home. Providing services in the home

are beneficial to families like those in the study, who have difficulty engaging in hospital services. The Department of Endocrinology at PMH is currently providing a holistic service to those that attend the hospital regularly; however a community-based multi-disciplinary team (MDT) would be beneficial for those that have difficulty attending hospital based services. Needs that are not currently met in the community are physical, medical, occupational and educational. Through a multidisciplinary (occupational therapy, physiotherapy, social work, education officer) community-based team, these needs could be met in the community. Provision of a multidisciplinary community-based service for families who have complex needs, and who have difficulty engaging in services, will help improve the health and quality of life of children with T1DM and their families in Western Australia.

Conclusion

This study further contributes to the knowledge on the experiences of T1DM for children/adolescents and their families; and is a starting point for understanding the impact of community-based psychosocial interventions for children/adolescents with T1DM and their families. Research has found that children/adolescents with T1DM are at more risk of having mental health difficulties than their peers. This study has provided support that psychosocial interventions conducted by health professionals have the potential to improve quality of life and outcomes for children and families that are affected by T1DM.

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Appendix A: Description of included studies

First author, year of publication	Design and sample	Intervention details	Psychosocial outcome measures	Results (Effect sizes reported where possible) ^a	Methodological quality ^{bc}
Whittemore. (2010)	RCT (n=12). Experiment = Internet coping skills training program (n=6); Control = Internet education program (n=6). Teenagers with T1DM (13-16 years).	Participants randomised to TEENCOPE or to Managing Diabetes Internet Intervention. TEENCOPE: Five weekly sessions on specific coping skills. Managing diabetes: Four weekly sessions on glucose control, nutrition, exercise, sick days and new technology. TEENCOPE: moderated by a clinical psychologist. Managing Diabetes: not moderated by a health professional.	<u>Quality of life</u> -Quality of life: Pediatric Quality of Life Inventory. <u>Mental health/psychological well-being</u> -Stress: Perceived Stress Scale. -Coping: Issues in Coping with IDDM-Child scale. -Self-efficacy: Self-efficacy for Diabetes Scale. -Psychosocial adjustment: Children's Depression Inventory <u>Client satisfaction</u> Acceptability: 5-item satisfaction survey (developed by authors).	<u>Quality of life</u> Quality of life: better treatment quality of life ($p=.20$). <u>Mental health/psychological well-being</u> Stress: less perceived stress ($p=.20$). Coping: better coping ($p=.07$). Self-efficacy: better diabetes self-efficacy ($p=.20$). Psychosocial adjustment: Improvement in scores of Children's Depressive Inventory. <u>Client satisfaction</u> Acceptability: Satisfaction with internet intervention was high. Satisfaction with intervention program was higher than that with the control ($p=0.12$).	Adequate quality (18/28=64%). Level 2 evidence
Sullivan-Bolyai. (2010)	RCT (n=58) Experiment = Social support from trained parent mentors (n=30); Control= untrained support (n=28). Parents of children	Social Support to Empower Parents (STEP): Social support intervention for parents of children <13 years old newly diagnosed with T1DM. Ten parent mentors. Mentors were matched as closely as	<u>Mental health/psychological well-being</u> -Concerns about diabetes management: Banion Concern Questionnaire. -Worry about raising a child with a chronic illness: The Worry Scale. Confidence in caring for a	<u>Mental health/psychological well-being</u> Concerns about diabetes management: NS. (ES= 0.11, small). Worry about raising a child with a chronic illness: NS. (ES= 0.004, small). Confidence in caring for a child with chronic illness: NS. (ES= 0.15, small). <u>Family functioning</u> Perceptions of impact on family: NS.	Adequate quality (18/28=64%). Level 2 evidence

	<13 years old newly diagnosed with T1DM.	possible to the newly diagnosed family in terms of child's age and gender. Intervention duration: 12 months.	child with chronic illness: Parental confidence Scale. <u>Family functioning</u> -Impact chronic illness has on the family: Impact on the Family Scale.	(ES= 0.005, small).	
Ellis. (2007)	RCT (n=127) Experimental = MST (n= 64) Control = Standard care (n=63). Children with T1DM (10-17 years) and their families.	MST: approximately 6 months of home and community-based psychotherapy plus standard medical care. Control: standard diabetes care only. Three therapists provided MST treatment.	<u>Family functioning</u> -Family relationships: Diabetes Family Behaviour Checklist and the Family Environment Scale.	<u>Family functioning</u> Family relationships Diabetes specific: Significant main effect of treatment condition was found for secondary caregiver support ($p<0.05$); (ES= 0.26, small) General family relationships: Small improvements in general family relationships.	Strong quality (23/28=82%) Level 2 evidence
Channon. (2007)	RCT (n=60). Experiment= Motivational interviewing (n= 35); Control = support visits (n= 25). Teenagers with T1DM (14-17 years old).	Motivational interviewing interventionist was in training as a health psychologist. Sessions lasted 20-60 minutes and finished after maximum of 12 months. Control group: 12 months of support visits by interventionist with a nursing background.	<u>Quality of life</u> -Quality of life: The Diabetes Quality of Life Measure for Youths. <u>Mental health/psychological well-being</u> -Locus of control in relation to health issues: The Child Locus of Control. -Autonomy support from health care providers: The Modified Health Care Climate Questionnaire. -Self-efficacy beliefs: The Self-Efficacy for Diabetes Scale. -Well-being: The Well-being Questionnaire.	<u>Quality of life</u> Quality of life: Satisfaction $p<0.001$, ES= 1.19 (large) ; Impact $p= 0.003$, ES= 0.7 (moderate); Worries $p<0.001$, ES= 1.34 (large). <u>Mental health/psychological well-being</u> Locus of control in relation to health issues: NS at 12 months; ES= 0.23 (small). Autonomy support from health care providers: NS at 12 months; ES= 0.37 (small). Self-efficacy beliefs: NS at 12 months; ES= 0.33 (small). Well-being: Depression $p=0.044$, ES= 0.87 (moderate); Anxiety $p=0.001$, ES= 1.86 (large); Energy $p=0.156$, ES= 0.48	Strong quality (24/28= 85.7%) Level 2 evidence

			-Personal models of illness: The Personal Models of Diabetes Scale. <u>Family functioning</u> -Diabetes-specific family support: The Diabetes Family Behaviour Scale.	(large); Positive well-being $p < 0.001$, ES= 1.31 (large); Total well-being $p < 0.001$, ES= 1.97 (large) (at 12 months). Personal models of illness: 12 months all subscales $p < 0.001$. Importance: ES= 2.15 (large); Likely: ES= 2.03 (large); Worry: ES= 1.14 (large); Agree/disagree: ES= 1.04 (large); Total: 1.82 (large). <u>Family functioning</u> Diabetes-specific family support: NS; ES= 0.54 (moderate).	
Nunn. (2006)	RCT (n=123). Experiment = bimonthly telephone support plus standard care (n=60); Control = standard care (n=63). Participants= individuals (3-16 years) with T1DM	Intervention= Bi-monthly phone calls lasting 15-30 mins from a paediatric diabetes educator.	<u>Mental health/psychological well-being</u> -Mental health: Strengths and Difficulties Questionnaire.	<u>Mental health/psychological well-being</u> Mental health: emotional score $p = 0.45$ (NS); conduct score $p = 0.34$ (NS); hyperactivity score $p = 0.90$ (NS); peer problems $p = 0.73$ (NS); prosocial score $p = 0.92$ (NS).	Good quality (19/28= 68%) Level 2 evidence
Lawson. (2005)	RCT (n=46) Experimental = telephone intervention plus standard care (n=23); Control = standard care (n=23). Adolescents 13-17 years with T1DM for	Intervention= 6 months of weekly, standardised telephone contact with the adolescent by a diabetes nurse educator.	<u>Quality of life</u> -Quality of life: Diabetes Quality of Life Scale for Youth (DQOLY) Questionnaire. <u>Family functioning</u> -Family functioning: Family Environment Scale.	<u>Quality of life</u> Quality of life: NS. Satisfaction with life: ES= 0.95 (large); diabetes impact: ES= 0.62 (moderate); diabetes worries: ES= 1.46 (moderate). <u>Family functioning</u> Family functioning: NS. Supportive factors: ES= 2.52 (large); conflicted factors: ES= 0.37 (small); controlling factors: 0.79 (large).	Strong quality (25/28= 89%) Level 2 evidence

at least 1 year.

Sullivan-Bolyai. (2004)	RCT (n= 41) Experiment = 6 months of home visits and phone calls from a parent mentor (n=22). Control = standard care (n=19). Mothers of young children (1-10 years old) newly diagnosed with T1DM.	Intervention= Parent mentors provided phone calls, home visits and emails to parents of children newly diagnosed with T1DM over 6 months.	<u>Mental health/psychological well-being</u> -Diabetes management concern: The Banion Diabetes Management Concern Questionnaire. -Maternal confidence: The Parental Confidence Questionnaire. <u>Family functioning</u> -Impact on the family: The Impact on Family Scale.	<u>Mental health/psychological well-being</u> Diabetes management concern $p= 0.02$ (significant reduction in diabetes-related concerns compared with control); ES= 0.18 (small). Maternal confidence $p= 0.44$ (NS); ES= 0 (small). <u>Family functioning</u> Impact on family: $p= 0.05$ (perceived impact of illness as less negative compared with control); ES= 0.08 (small).	Adequate quality (18/28= 64%) Level 2 evidence
Ireys. (2001)	RCT (n=139); total number with T1DM (n=55). Experimental group= (n=73). T1DM experimental group = (n=29); Control group= (n=66); T1DM control group (n=26). Mothers of children (7-11 years) diagnosed with diabetes, sickle cell anaemia, cystic fibrosis, or moderate to severe asthma.	Intervention= 15 month intervention, designed to enhance mothers' mental health by linking mothers of school-aged children with selected chronic illnesses with mothers of older children with the same condition. The program included telephone contacts, face- to-face visits, and special family events.	<u>Mental health/psychological well-being</u> -Maternal anxiety: Anxiety subscale of the Psychiatric Symptom Index (PSI). -Maternal depression: 21-item Beck Depression Inventory.	<u>Mental health/psychological well-being</u> Maternal anxiety: Experimental group reported lower levels of anxiety post intervention compared to baseline scores. $p=0.03$; ES= 0.39 (small). Maternal depression NS.	Good quality (20/28= 71.4%) Level 2 evidence

Harris. (2005)	Pre-experimental (n=17). 6 month follow-up. 17 adolescents with poorly controlled diabetes (aged 13-18 years) with T1DM and their families.	Intervention= In-home Behavioural Family Systems Therapy. Ten 90 minute sessions of in home-BFST over 5-8 weeks. Sessions conducted by a master's level social worker and doctoral level psychologist in training (both trained in BFST).	<u>Mental health/psychological well-being</u> -Child's behaviour and psychological status: Child Behaviour Checklist. -Self-acceptance and acceptance from others: Adjustment to Illness Scale. <u>Family functioning</u> -Diabetes-related conflict: The Diabetes Responsibility and Conflict Scale. -Supportive and non-supportive family behaviours: Diabetes Family Behaviour Checklist. -General conflict between parents and their children: Conflict Behaviour Questionnaire.	<u>Mental health/psychological well-being</u> -Child's behaviour and psychological status: NS. Teen (ES= 0.31-small); Mother (ES= 0.34-small); Father (ES= 0.15- small). -Diabetes-related adjustment: Teen (ES= 0.09- small); Mother (ES= 0.13-small); Father (ES= 0.30- small). -Self-acceptance and acceptance from others: NS. <u>Family functioning</u> -Diabetes-related conflict: NS. Teen (ES= 0.46- moderate); Mother (ES= 0.31-small); Father (ES= 0.12- small). -Supportive family behaviours: NS. Teen (ES= 0.36-small); Mother (ES= 0.20- small); Father (ES= 0.33-small). -Non-supportive family behaviours: NS. Teen (ES= 0.59- moderate); Mother (ES=0.25- small); Father (ES= 0.06-small). -General conflict between parents and their children: NS. Teen (ES= 0.05 small); Mother (ES= 0.46 moderate); Father (ES= 0.45-moderate).	Adequate quality (14/22= 63.6%) Level 4 evidence
Harris. (2003)	Pre-experimental Post-treatment results. 17 adolescents with poorly controlled diabetes (aged 13-18 years) with T1DM	Intervention= In-home Behavioural Family Systems Therapy. Ten 90 minute sessions of in home-BFST over a period of approximately 5-8 weeks. Sessions conducted by	<u>Mental health/psychological well-being</u> -Child's behaviour and psychological status: Child Behaviour Checklist. -Self-acceptance and acceptance from others: Adjustment to Illness Scale.	<u>Mental health/psychological well-being</u> -Child's behaviour and psychological status: CBCL internalising subscale $p=0.002$; externalizing subscale $p=0.000$. Teen (ES= 0.18- small); Mother (ES= 0.72- large); Father (ES=0.29 (small). Internalising behaviour: Teen (ES= 0.39-small); Mother (ES= 0.58-moderate);	Adequate quality (13/20)=65% Level 4 evidence

	and their families.	two professionals trained in BFST.	<u>Family functioning</u> -Diabetes-related conflict: The Diabetes Responsibility and Conflict Scale. -Supportive and non-supportive family behaviours: Diabetes Family Behaviour Checklist. -General conflict between parents and their children: Conflict Behaviour Questionnaire.	Father (ES= 0.18-small). Externalising behaviour: Teen (ES= 0.22- small); Mother (ES= 0.73- large); Father (ES=0.15- small). -Diabetes-related adjustment: Teen (ES= 0.22- small); Mother (ES= 0.02 (small); Father (ES= 0.13- small). -Self-acceptance and acceptance from others: NS. <u>Family functioning</u> -Diabetes-related conflict: Significantly less conflict $p=0.002$ reported by mothers. Teen (ES= 0.38-small); Mother (ES=0.53- moderate); Father (0.06-small). -Supportive behaviours: NS. Teen (ES= 0.03- small); Mother (ES= 0- small); Father (ES= 0.51- moderate). -Non-supportive behaviours: NS. Teen (ES= 0.28- small). Mother (ES= 0.35-small); Father (ES= 0.14- small). -General conflict between parents and their children: NS. Teen (ES= 0.31-small); Mother (ES= 0.91- large); Father (ES= 0.47- moderate).	
Channon. (2003)	Pre-experimental (n=22). 22 Adolescents with T1DM (14-18 years).	Intervention= Motivational interviewing sessions for 6 months. Sessions conducted by the researcher who was trained in motivational interviewing.	<u>Mental health/psychological well-being</u> -Well-being: The Well-Being Questionnaire. -Participants' personal models of diabetes: Personal Models of Diabetes Questionnaire.	<u>Mental health/psychological well-being</u> Well-being: NS Participants' personal models of diabetes- significant reduction in fear of hypoglycaemia ($p=0.03$) and living with diabetes score ($p=0.03$) indicating diabetes was easier to live with. <u>Family functioning</u>	Limited quality (9/22= 40.1%) Level 4 evidence

Family functioning

-Family process: Family
Adaptability and Cohesion
Evaluation Scales.

-Family behaviours: Diabetes
Family Behaviour
Scale.

Family process: NS

Family behaviours: NS

Note: ^a = Assessed according to Thomas JR, Nelson JK. Research methods in physical activity. 4th Ed. Library of Congress Cataloging-in-Publication Data, Champaign, Illinois, 2001.

^b = Kmet L, M, Lee RC, Cook L, S. Standard quality assessment criteria for evaluating primary research papers from a variety of fields. Alberta Heritage Foundation for Medical Research, 2004.

^c = National Health and Medical Research Council. A guide to the development, implementation and evaluation of clinical practice guidelines [Internet].

Retrieved from http://www.nhmrc.gov.au/_files_nhmrc/file/publications/synopses/cp30.pdf. 1999

NS= Not significant; ES = Effect size; RCT = Randomised controlled trial; T1DM = Type 1 Diabetes Mellitus

Appendix B

Type 1 diabetes

Child/Adolescent guide

Demographic information: Will be obtained by parent filling out demographic questionnaire on behalf of the child.

Ask child:

- How long have you had diabetes?
- How many insulin injections do you need to have per day? Or do you use an insulin pump?

Broad question:

How do you feel the community mental health nurse (CMHN) has impacted on you and your family?

- **What has changed since the CMHN has been around?**

IMPACT

1. **What's it like having diabetes?**
2. **Do you remember how old you were when you were diagnosed with diabetes?** *If yes, do you remember your life before having diabetes? If yes, how has your life changed?*

MENTAL HEALTH

3. **How does having diabetes affect you?** How does it make you feel? E.g does it make you feel happy, sad, angry etc. Does it affect your friendships? E.g going to your friends house, sleepovers, do they understand your routine? Does it affect your sleep? Eg having to wake up in the night? How do you feel about this? What is your daily routine? Have you found that having diabetes means you have to do things differently each day than other kids? Eg eat at certain times, take time out to take insulin, at school..do you have to see the school nurse more than others.
4. **Do you think that you having diabetes affects other people in your family?** Mum, dad? Do you think they worry about you? Do they have to wake up during the night to help you with your insulin or give you food to manage you blood glucose levels?

CMHN

5. What do you think the CMHN does for a job?
6. How do you feel about having the CMHN in your life? Does he help you manage your condition?
7. What are your experiences of working with the CMHN?

Is he:

- *Convenient?*
- *Flexible (working/visiting hours);*
- *What has been helpful and what has not been helpful?*
- *Noticed improvements?*
- *What are the benefits?*
- *Differences between community and clinic? (Pros and cons).*
- *Has the CMHN referred you to other services such as the Youth Club or any other services and have they been helpful/not so helpful?*
- *School involvement- has it been helpful or unhelpful?*
- *Do you feel your opinion is taken into account? Do you feel involved in plans of action (client-centred?).*
- *Have you noticed any changes as a result of the CMHN's involvement in your life? They can be positive or negative. Has your knowledge improved re: condition; coping skills; adaptive behaviours; communication...*
- *What are you doing differently as a result of the service and visits and the CMHN's guidance?*

5. How have the CMHN's home visits impacted on your life?

- *Self-care: daily routine, sleep, meal times...*
- *Productivity: school- does he liaise with the school? Does he help with anything like teasing or bullying?, part time work? (if applicable),*
- *Leisure: friends, hobbies, sport, going out to dinner, parties, sleep-overs*
Note: terms 'self-care', 'productivity' and 'leisure' will not be used in conversation.
- *Does he see the whole family? How do you feel about him seeing the whole family?*

6. What could the CMHN do to improve? What do you particularly like about the service the CMHN provides?

7. Any further comments?

Type 1 diabetes

Parent guide/Guardian guide

Demographic information of parent(s):

- Will be obtained using demographic questionnaire.

Demographic information of child (that is not covered in demographic questionnaire):

- Onset of illness
- Other medical conditions
- Current services received by the child at PMH
- Other services provided for child/adolescent
- Duration of diabetes?
- Number of injections daily or insulin pump?

Broad question:

How do you feel the community mental health nurse (CMHN) has impacted on you, the rest of the family, and on (insert child's name)?

- **Have there been any changes in the way the family functions since the CMHN has been working with you?**

IMPACT

1. How has (child's name) having diabetes impacted on the family?

- Positively
- Negatively

2. How has (child's name)'s diabetes impacted on your life?

- Self-care: sleep patterns, daily routines, meal-times
- Productivity: work, your relationship with the school?
- Leisure: hobbies, exercise
- Who is mostly responsible for the management of the diabetes?

Note: terms- self-care, productivity and leisure will not be used and will be described by interviewer.

3. How do you think (child's name)'s diabetes has impacted on his/ her life?

- Self-care
- Productivity: school, any teasing or bullying?
- Leisure (These terms will be explained)

MENTAL HEALTH

4. Have you noticed any changes in yourself following (child's name) being diagnosed with diabetes?

Prompts:

- Before and after diagnosis
- Before and after receiving services from the CMHN
- Changes that you noticed upon diagnosis and in the following years
- Changes in mood
- Behaviour
- Emotional reactions
- Communication
- Friends
- Sleep patterns
- Memory
- Independent functions such as ADL's and IADL's. (These terms will be explained)

5. Have you noticed any changes in the family following (child's name) being diagnosed with diabetes?

- Before and after diagnosis
- Before and after receiving services from the CMHN
- Changes that you noticed upon diagnosis and in the following years
- Changes in mood
- Behaviour
- Emotional reactions
- Communication
- Social interaction
- Sleep patterns
- Memory
- Independent functions such as ADL's and IADL's. (These terms will be explained)

6. Have you noticed any changes in (child's name) following him/her being diagnosed with diabetes?

- Before and after diagnosis
- Before and after receiving services from the CMHN
- Changes that you noticed upon diagnosis and in the following years
- Changes in mood
- Behaviour:
- Emotional reactions
- Communication
- Social interaction
- Sleep patterns
- Memory
- Independent functions such as ADL's and IADL's (explain these)

CMHN**7. What is your opinion of the CMHN's role? What expectations did you have of the CMHN?****8. What are your experiences of working with the CMHN?**

Is he:

- *Convenient?*
- *Flexible (working/visiting hours);*
- *What has been helpful and what has not been helpful?*
- *Have you noticed results following action plans developed by you and the CMHN?*
- *What are the benefits of being involved in the CMHN's service?*
- *Differences between community and hospital care (pros and cons).*
- *Has the CMHN referred you to other services such as the youth club or any other services? Have they been helpful?*
- *School involvement- has it been helpful or unhelpful?*
- *Do you feel your opinion is taken into account?*
- *Do you feel involved in plans of action (client-centred?).*
- *Is the CMHN reliable and does he follow up on what he says he is going to do?*
- *What changes have you noticed? Has your knowledge improved re: condition; coping skills; adaptive behaviours; communication.*
- *Are you doing anything differently as a result of the visits and guidance the CMHN provided?*

9. How has the community mental health nursing mode of service delivery impacted on your life (COPM)?

- Self-care:
 - Productivity:
 - Leisure:
- (These terms will be explained)

10. Has the service met your expectations?

11. What could the CMHN do to improve? What do you particularly like about the service the CMHN provides?

12. Any further comments?

Appendix C

Assessment results (n=11)

Family	CSQ-8	DQLYM	CBCL	GF-FAD
Mum and Dad	32	Impact=65; Worries=26	Externalising score= 56	1.1
Son, 15 y.o	29	Impact=65; Worries=37	Externalising score= 57	2.1
Mum	31	Impact=54; Worries=23	Externalising score= 55	2.2
Daughter, 13 y.o	22	Impact=41; Worries=16	Externalising score= 68	1.8
Mum	30	Impact=55; Worries=15	Externalising score= 65	2.0
Daughter, 16 y.o	32	Impact=45; Worries=15	Externalising score= 58	1.1
Mum	31	Impact=46; Worries=55	Externalising score= 53	2.8
Son, 11 y.o	-	-	-	-
Dad	30	-	Externalising score= 82	2.1
Son, 16	-	-	-	-
Mum	25	Impact=74; Worries=32	Externalising score= 72	1.4
Son, 15 y.o	25	Impact= 68; Worries=25	Externalising score= 62	2.8

Note: Dashes indicate the data were not obtained

CSQ-8 (Client Satisfaction Questionnaire-8) = Scores can range from 8-32. Higher scores = greater satisfaction.

DQLYM (Diabetes Quality of Life for Youth Measure) = I=Impact of diabetes (scores can range from 24-115); W= Worries about diabetes (scores can range from 11-55). The higher the value, the higher perceived negative quality of life.

CBCL (Child Behaviour Checklist) = *T* scores for Externalising problems are given.

GF-FAD (General Functioning Subscale from the McMaster Family Assessment Device) = Scores can range 1-4. Higher scores= greater family pathology.

Appendix D: Main themes from the semi-structured interviews

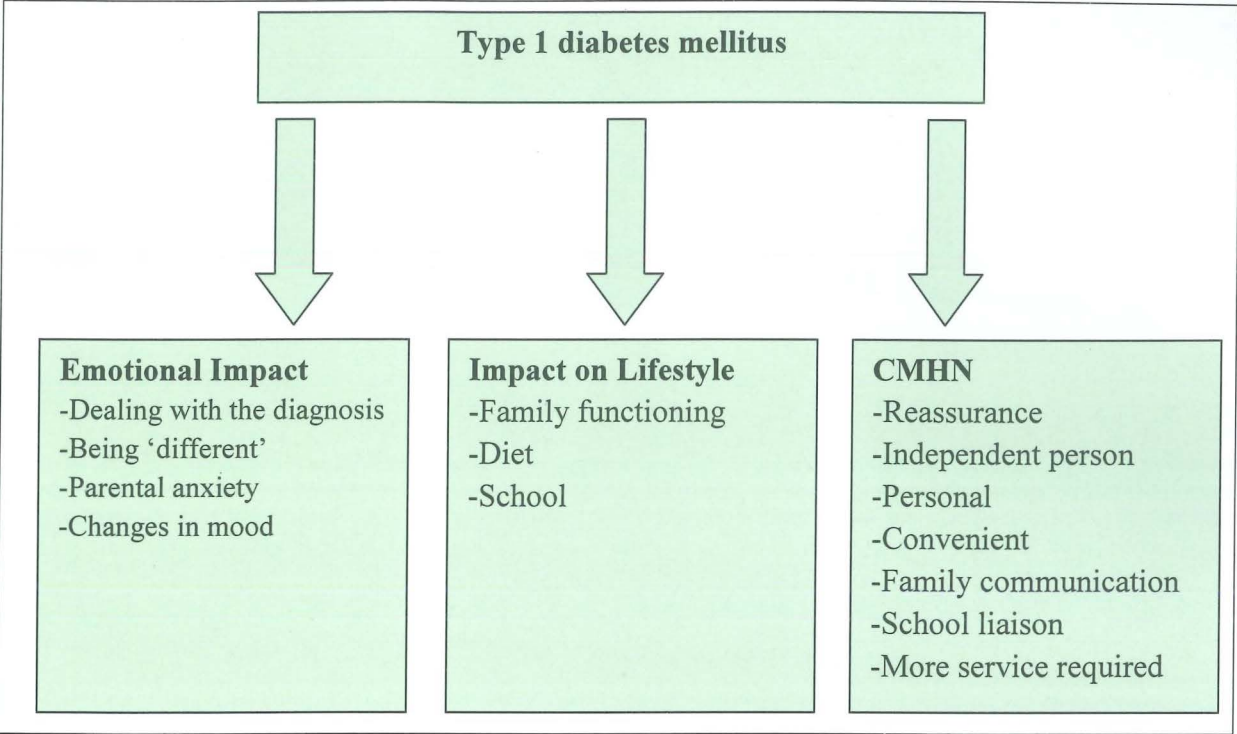


Figure 1. Main themes from the qualitative interviews. CMHN = Community mental health nurse

Guidelines for contributions by authors

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