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- Abstract booklet -

Title: Pilot study of clinician attitudes to insulin pump therapy: international differences and the need for a greater understanding of the patient perspective

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Aims: Willingness to recommend insulin pumps to patients varies between diabetes specialist care teams. Few healthcare professionals (HCPs) are experts in the use of insulin pump therapy (CSII), and diabetes specialist nurses (DSNs) are often expected to provide support for CSII use without appropriate training. The aim of this work was to identify and survey HCPs attitudes to CSII therapy.

Methods: 8 specialists (3 diabetologists, 2 DSNs and 3 dieticians) were interviewed to explore the attitudes and beliefs about CSII. Responses were analysed thematically and used to inform the design of a new 22-item questionnaire: the Attitudes to Pump Therapy (APT) Survey. The APT was pilot-tested among 95 HCPs (54% male; 75.5% diabetologists/DSNs, 13.8% general practitioners) at the International Diabetes Federation (IDF) conference, 2006. Results were analysed using non-parametric statistics with bonferroni correction.

Results: Analyses of interview data identified 8 themes: biomedical, perceived control of care/diabetes, technology, quality of life, financial resources, training, education & support, suitability, and evidence-base. The APT items were designed to reflect these themes with responses scored on a 5-point Likert scale (strongly agree – strongly disagree). No statistically significant differences were found by gender, HCP speciality, country (and continent) of origin or proportion of patients on pumps. Analysis was also conducted by country of origin grouped and dichotomised by gross domestic product (GDP) (≤ 100 bn US\$ (i.e. under-developed and Eastern European countries) vs > 100 bn US\$). Clinicians from lower GDP countries showed greater agreement with the statement “People using CSII therapy are more likely to achieve tight blood glucose control than people on other regimens” ($U=410.0$, $p=0.001$), and less agreement with the statement “CSII therapy is more likely to result in diabetic ketoacidosis (DKA) than other insulin regimens” ($U=387.5$, $p<0.005$). Observation of ranked mean scores showed a split between biomedical/clinical items ($N=11$) and items concerned with patient experience ($N=11$). Attitudes about biomedical/clinical issues were generally clear (i.e. for 7/11 items, the mean score was “agree”) while clinicians were less decisive about patient experience (i.e. for 8/11 items, the mean score was “neither agree nor disagree”). Subgroup differences (e.g. GDP, HCP speciality) in response patterns were identified.

Conclusions: This pilot study confirms the need to investigate beliefs about CSII therapy. Few subgroup differences were observed, but those that were may be explained by lack of access to treatment (directly corresponding to GDP). Research focusing on patient-reported outcomes is likely to offer clinicians a greater understanding of the patients’ perspective. The APT Survey is currently in preparation for a UK-based validation study.

Title: Cognitive processing of food stimuli and its relationship to dietary self-care in type 2 diabetes

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Abstract:

Successful modifications in eating habits according to dietary self-care recommendations for type 2 diabetes (t2D) are thought to reduce the risk of diabetes-related complications. Yet, many patients with t2D have difficulty following these recommendations. In a pilot study, 7 patients with t2D and 5 non-diabetic control participants were presented with pictures showing low and high calorie foods and no-food control images. Activation in regions associated with gustatory (insula) and motivational/affective (amygdala and OFC) processing was examined and correlated with self-reported adherence to dietary recommendations.

Regions that were activated in both healthy and t2D participants in response to food stimuli included the right amygdala and right insula where a larger response to food vs. no food was found. Food liking modulated activation in the bilateral amygdala, bilateral OFC and the right insula. Furthermore, bilateral insula and right OFC showed differential response to high vs. low calorie food stimuli.

Differential activation between t2D and non-diabetic participants were observed in right insula in response to food stimuli. In non-diabetic individuals, left OFC and right insula showed activation, which was better associated with food liking than activation observed in t2D patients. Intriguingly, in t2D patients we found that the extent of differential response in bilateral amygdala and right insula to low vs. high calorie foods predicted the dietary adherence. These results suggest that having t2D with its associated dietary requirements may change the way food stimuli are processed in the gustatory- and motivational/affective brain regions. Furthermore, adherence to dietary recommendations may have neurological correlates in emotion-related brain regions.

Title: The dose adjustment for normal eating (DAFNE) trial: improvements in HbA1c still apparent and quality of life benefits well maintained at 4-year follow-up

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Background: The Dose Adjustment For Normal Eating (DAFNE) trial was a waiting-list-controlled study of 5 days' training in flexible, intensive insulin therapy in a group of 135 adults with Type 1 diabetes in the UK. At 6 months (m), DAFNE improved glycaemic control without increasing severe hypoglycaemia, while significantly reducing the negative impact of diabetes on quality of life (QoL) and improving other patient reported outcomes (PROs).

Aims: To evaluate long-term efficacy of DAFNE training.

Methods: At 44m follow-up (range: 37-51m), 108 (80%) trial participants provided biomedical data and 88 (65%) completed questionnaires, including ADDQoL (measuring impact of diabetes on QoL).

Results: At 44m, HbA1c ($8.96 \pm 1.2\%$) had deteriorated from 12m ($8.75 \pm 1.2\%$, $p < 0.05$) but remained improved from baseline ($9.32 \pm 1.1\%$, $p < 0.01$). All QoL outcomes remained significantly improved from baseline with no difference between 12m and 44m (e.g. impact of diabetes on dietary freedom: -1.78 ± 2.33 at 44m vs -4.27 ± 2.94 at baseline, $p < 0.0001$; vs 1.80 ± 2.32 at 12m, ns).

Conclusions: The impact of a single DAFNE course on glycaemic control is reduced but still apparent in the long term. Additional input may be needed to maintain the initial response. In contrast, improvements in QoL and other PROs were well maintained over approximately 4 years.

Title: Beliefs about medicines and personal models of diabetes in relation to adherence to medication in patients with type 2 diabetes

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Aims: To explore the relationship between beliefs about medication, personal models of diabetes and adherence to medication in patients with type 2 diabetes.

Methods: 133 participants with type 2 diabetes, aged 35-70 and treated exclusively with OHA prescriptions for more than 1 year, completed questionnaires assessing beliefs about medicines, personal models of diabetes, satisfaction with treatment, self-efficacy for and barriers to medication taking, knowledge about prescriptions and a subjective measure of adherence.

Results: Most (90%) participants believed that specific medicines prescribed for their diabetes were effective and necessary. However, 60% were worried about the potential long term effects of this medication and 25% felt that medicines were overused by doctors. Personal models of diabetes were related to more general beliefs that medicines are harmful addictive substances, to forgetting to take medication ($p = .004$), altering the dose to suit personal needs ($p = .016$), a perception of being able to cope without medication ($p = .003$) and self-efficacy for medication taking ($p = .001$). Lower self-efficacy was related to higher HbA1c ($p = .008$) and BMI ($p = .004$).

Conclusions: These results will be discussed in terms of the complex beliefs that people hold about their medication and diabetes which may have a significant impact on self-management and influence adherence to treatment.

Title: Treatment satisfaction in Type 2 Diabetes mellitus – development and evaluation of a self-care anchored instrument (ITEQ)

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Aims: Treatment satisfaction (TS) is a key outcome criterion of diabetes therapy. Common instruments for assessing TS, however, usually measure TS as a high-level construct (e.g., DTSSQ) and mostly unrelated to actual self-care behavior and tangible effects of diabetes therapy. Though this clearly is advantageous with regard to the instruments flexibility and economy in its application, high level TS most probably fails to capture subtle effects of different types of insulin regimens (e.g. BOT, intensified insulin therapy with or without insulin analogues) on TS, as they do not reflect actual effects on self-care behaviour. Hence, this study's aim was to develop a questionnaire (Insulin Treatment Experience Questionnaire; ITEQ) for assessing TS with a particular focus on self-care effects of different forms of insulin therapy, focusing on T2DM patients.

Methods: In a first step, qualitative interviews were conducted with N = 28 T2DM outpatients (age M±SD: 60.5±11.3; range 39-81 years, 44.0% male) and a initial set of 42 items was generated on the basis of the content analyses of the transcribed interviews. The preliminary instrument was, then, completed by a second sample of T2DM outpatients (n = 62, age M±SD: 62±11; range: 27-88 years, 43.5% male). In addition, a random subset of this sample participated in a qualitative interview in order to check for the items' comprehensibility and face validity. These interviews' as well as the psychometric analyses' results were used for the final instrument's construction.

Results: The final version of the questionnaire comprises 28 items with the subscales „leisure activities“ (4 items), „psychological barriers“ (2 items), „handling“ (5 items), „diabetes control“ (6 items), „dependence“ (5 items), „weight control“ (3 items), „sleep“ (2 items) as well as one item assessing general TS. The subscales' internal consistencies (Cronbach's α) ranged from $\alpha = .55$ to $\alpha = .87$, with $\alpha = .83$ for the whole instrument. The mean part-whole corrected item-score-correlation was $r_i(t-i) = .35$, with a reliability of $r = .72$ (Spearman-Brown). PCA was used to ensure construct validity (66% of variance explained).

Conclusions: The newly developed questionnaire showed satisfying to good psychometric properties and offers the opportunity of assessing TS as a function of actual self-care behaviour. Currently, the questionnaire is being used in a large scale multi-centre trial to gain further insights into its validity and sensitivity to change.

Title: The use of puppets in education of children with diabetes

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Background: The use of playthings is generally recommended to support the general learning process of children. Playthings can also be used in therapeutic patient education programmes to help chronically ill children develop the cognitive and psychosocial skills necessary to manage their disease. In particular, the creation and use of puppets have proven to be a very effective means of enhancing the learning process of diabetic children.

Methods: Puppets have been introduced for four years in patient education programmes developed for diabetic children attending holiday camps in France. Two programmes where puppets are used to reinforce or develop cognitive and psychosocial skills respectively have been videotaped and evaluated so as to issue recommendations for practice. The programmes were evaluated, using quantitative and qualitative methods. Specific child-friendly evaluation tools were created.

Results: Puppets have proven to be an efficient tool to help children reinforce both cognitive and psychosocial skills. The overall learning and teaching process was enhanced, as both the children and the educators benefited from the use of puppets.

Conclusion: Puppets are a creative means of developing skills. The way they are used should vary according to the type of skills that are to be developed, ie. cognitive or psychosocial. Puppets can usefully be introduced in a therapeutic patient education programme. They can effectively contribute to the objectives of the programme only if the programme is well-structured, with clearly identified objectives aiming at enhancing the children's knowledge about their disease and treatment, as well as their general coping capacities.

Title: Adolescents and young adults with diabetes type 1 at CAMP-D: quality of life, metabolic control and satisfaction with long-term care during the phase of transition

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Aims: Diabetes in puberty is often regarded as difficult to be treated. However, quality of diabetes care in young adults during this first phase of developing personal autonomy has rarely been studied. Thus, the purpose of this study was to assess their treatment satisfaction, quality of life, diabetes-related psychosocial burden and metabolic control.

Methods: 409 participants of CAMP-D (a German nationwide diabetes-camp with 446 young people) aged 16-25 yrs. (mean age: 19.6 ± 3.2 yrs., diabetes duration: 8.2 ± 5.5 yrs., 55% female) completed questionnaires on their subjective wellbeing (WHO-5), diabetes related psychosocial stress (PAID, Polonsky 1995), satisfaction with diabetes long-term care (6-point-rating scales), diabetes treatment and their psychosocial situation. In addition, HbA1c was assessed at the camp (DCA2000+).

Results: 397 participants (97%) were on intensified insulin therapy – 153 (37%) with an insulin-pump – , and 378 (92%) were cared for by a certified diabetologist (German Diabetes Association). Median of HbA1c was 8.0% (37% of participants HbA1c < 7.5%; 28% HbA1c > 9%). While diabetes-related psychosocial stress (PAID) scored quite low (PAID total: 19.7 ± 13.6 ; range 0 - 100), subjective overall psychological wellbeing (WHO-5) was rather poor (mean 14.6 ± 4.6 ; range 0 -25). Multivariate analysis revealed systematic relationships between HbA1c and subjective well-being ($\rho = -0.13$; $p = 0.02$) and diabetes related stress ($\rho = 0.16$; $p=0.001$). All three variables were significantly related to educational level and parents' marital situation (living together or apart/divorced; each $p < 0.05$). HbA1c of the 189 adolescents (age < 19 yrs.) was higher than that of young adults (median 8.3 vs.7.7; $p=0.004$). Overall diabetes care was assessed positive (score: 1.8 ± 1.0), while nutritional advice (score: 2.6 ± 1.3) and psychosocial care (score 2.6 ± 1.4) were less positive. There was a strong association between satisfaction with diabetes-team and quality of psychological care ($\rho = 0.52$; $p = 0.001$).

Conclusions: Despite good technical equipment and qualified care by diabetologists, only 37% of the nationwide sample achieved the therapeutic goal of HbA1c < 7.5%. In one third of the young people the subjective emotional well-being was poor. One predictor for both of these variables was the situation of the parents, particularly in terms of living together or apart. Correspondingly, the participants mentioned deficits in psycho-social care. The multi-professional team concept of paediatric care concentrating on both the somatic and the psychosocial situation of young people with diabetes should be extended to young adulthood.

Title: Quality of life in children with type 1 diabetes and psychological burden in parents during the first year after diabetes onset: a prospective multicentre study

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Aims: The diagnosis of type 1 diabetes represents a critical life event to children and their parents and requires numerous adjustments in every day life. Treatment targets include good metabolic control as well as good quality of life and emotional well-being of the child and its family. In a prospective study these treatment targets were assessed at diagnosis and at 6 and 12 months following diabetes onset.

Methods: In 10 German paediatric diabetes centres 81 families of children (age 4–14 yrs.; 8.1 ± 2.9 yrs.) with newly diagnosed type 1 diabetes were included into the study. At onset (t0) parents completed a validated questionnaire (KindlR) on their child's health-related quality of life (HRQoL) before diagnosis and a questionnaire on their own well-being at present (WHO-5). Both questionnaires were completed again after 6 (t1) and 12 month (t2). In addition metabolic control (HbA1c) and social attributes of the children were assessed.

Results: 81 mothers (9 single mothers) and 74 fathers were initially included, at (t1) 75 m./71 f., (t2) 77 m./71 f.. Children's health-related quality of life before onset in all but one of the KindlR-subcales corresponded to standard values of healthy controls. Only physical well-being was rated as significantly worse (64 ± 18 vs. 57 ± 23 ; $p < 0.01$). At t1 and t2 parents assessed their children's HRQoL significantly better than before onset and than the standard values of healthy controls (subcales: physical well-being, psychological well-being, self-esteem, kindergarten/school and total HRQoL, each $p < 0.001$). Metabolic control at onset (mean HbA1c) was $10.8 \pm 2.7\%$, while after 6 months it went down to $6.8 \pm 1.0\%$ and to $7.2 \pm 1.2\%$ after 12 months. Compared to standard values of WHO-5 mothers' psychological well-being was poor (sum-scores: (t0) 11.9 ± 6.9 ; (t1) 12.8 ± 5.5 ; (t2) 14.5 ± 5.0), while fathers reached significant better scores (sum-scores: (t0) 15.8 ± 6.0 ; (t1) 15.4 ± 5.1 ; (t2) 16.5 ± 5.1) at every time ($p < 0.001$). Scores < 13 (indicating depression) were seen at 50% (t0), 41% (t1) and 29% (t2) of the mothers. After one year following diagnosis mothers' well-being improved significantly ($p = 0.002$). There was a systematic association between children's HRQoL and their mothers' psychological well-being (t0: $r = 0.47$; t1: $r = 0.48$, t12: $r = 0.35$; each $p < 0.001$).

Conclusions: In the first year following diagnosis, HRQoL of children with diabetes was unexpectedly good and paradoxically better than in healthy controls. However, the great psychological burden of mothers indicates their need for specialized care, given well-known negative effects of maternal depression on children's metabolic control after the remission phase are known. Thus, early support interventions for mothers concerned should be developed and evaluated for their utility to sustainably improve their family's emotional and physical health.

Title: Definition of age-related «educational profiles» to enhance the efficacy of therapeutic education of children and adolescents with type1 Diabetes

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Aims: Therapeutic education of children and adolescents with type 1 diabetes is an important part of care. Health behaviours are influenced by life situations, which are essential to know in an educational relationship. For 50 years, the French association AJD (Help for diabetic youth) has organised educational camps for diabetic children aged 5-18 years.

Methods: In order to better understand the needs and priorities of children according to their age, the «educational profile» of 1080 children who attended such camps in 2005 was studied. The aim was to characterize specific determinants of the efficacy of therapeutic education according to different age brackets (5-6, 7-8, 9-12, 13-15, 16-18 years), corresponding to developmental stages that influence the children's cognitive, psychological, social, and moral abilities. We distinguished «primary» determinants, such as gender, social situation of family, clinical and biological data, and participation in an AJD camp before, from «secondary» determinants, such as knowledge, autonomy, motivations, behaviours, and the experience of illness. We conducted individual semi-structured interviews to establish an educational diagnostic for every child, at the beginning and at the end of the stay. We used the interviews to first perform a qualitative content analysis, and then describe and statistically compare (t-test, ANOVA...) all the factors (dependent variables) according to age brackets.

Results: The age-related «educational profiles» were found to be influenced more by «secondary» determinants. We will present the specific results, and discuss their implications for the practice of patient education activities.

Title: Negative appraisal of insulin therapy and depression in insulin-naive patients with type 2 diabetes mellitus

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Aims/hypothesis: In many patients with type 2 diabetes the initiation of insulin therapy is postponed, leading to suboptimal glycemic control. Recent meta-analyses concluded that depression is a common problem in people with diabetes that is associated with poor glycemic control. The aim of the present study is to determine whether depression and diabetes-specific emotional problems are associated with a more negative appraisal of insulin therapy.

Subjects and methods: We collected cross-sectional data in two outpatient university clinics in Istanbul, Turkey. The study sample consisted of 154 men and women with type 2 diabetes aged on average 56 ± 10 years. A self-report questionnaire was used to obtain demographic and clinical data. Main outcome measures were the Center for Epidemiologic Studies Depression Scale, the Problem Areas in Diabetes Survey and the Insulin Treatment Appraisal Scale (ITAS).

Results: Analysis of variance revealed that patients with a high depression score rated insulin therapy significantly more negatively compared to patients with lower depression scores. Moreover, 47% of patients with a high depression score had a negative appraisal of insulin therapy on 7 or more ITAS-items, compared to 25 to 29% of those with low-moderate depression. Multiple regression analyses showed that a negative appraisal of insulin therapy was significantly associated with depression (Beta: 0.18) or diabetes-specific emotional problems (Beta 0.40) but not with level of education, sex, age or body mass index.

Conclusions/interpretation: Depression and diabetes-specific emotional distress are positively associated with negative beliefs about insulin therapy. Further longitudinal research is needed to investigate whether insulin therapy is indeed more frequently postponed in depressed or distressed patients with type 2 diabetes, and whether this is associated with worsened glycemic control.

Title: Parent and teenager views about treatments for diabetes during qualitative design work on two condition specific questionnaires: the DTSQ-parent and DTSQ-teen

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Aims: The eight-item Diabetes Treatment Satisfaction Questionnaire (DTSQ) is widely used for adults but its content is too abstract for young children and it does not necessarily address aspects of treatment important to children, teenagers and their parents. This study aimed to design DTSQ measures for completion by the parents of children with diabetes and by teenagers with diabetes.

Methods and Patients: Semi-structured tape-recorded interviews were conducted with 32 parents of children with diabetes, aged 5-17, and with 14 teenagers with diabetes, aged almost 13 to 17. Each gave their views about past and present treatments and then completed a draft questionnaire, which was changed between blocks of interviews to incorporate perspectives and priorities of interviewees. Later interviewees (13 parents; 6 teenagers) completed their questionnaire without first answering open-ended questions. Wording was refined to ensure instructions and items were understood as intended. Opinions were sought on font and layout.

Results: In response to open-ended questions, parents and teenagers mentioned spontaneously some aspects of treatment included in the adult DTSQ (e.g. high/low blood sugars, flexibility). Additionally, both parents and teenagers talked about diabetes control, about treatment fitting into the school/college day, interfering with what the child/teenager likes doing, discomfort/pain, how easy/difficult treatment was found to be and support from the hospital diabetes team. Parents (not teenagers) mentioned impact of treatment on family life. Six adult DTSQ items were retained (four with modifications). Seven additional items for parents (six for teenagers, excluding family life) ensured face and content validity. Teenagers chose Arial font. The DTSQ-Teen and -Parent have since undergone cognitive debriefing in Canada to ensure suitability of wording and data collection is underway.

Conclusions: The DTSQ-Parent and DTSQ-Teen have good face validity and are ready for data collection. Similar item content allows comparison between parent and teenager views.

Title: Well-being in diabetes outpatients: results of routine assessment as part of the annual review – first findings from the DAWN MIND STUDY

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Aims: International guidelines advocate systematic monitoring of well-being as integral part of diabetes care. In previous research, we demonstrated feasibility and effectiveness of a nurse-led computer-assisted assessment procedure. Aim is to implement and evaluate pc-assisted monitoring of psychological well-being by the diabetes nurse specialist (DNS) as integral part of ongoing outpatient care for adults with diabetes. Data on well-being and glycaemic control of the first 301 patients included in this ongoing project, are presented here.

Methods and patients: A computerised assessment programme was developed, including the WHO-5 Well-being Index and the Problem Areas in Diabetes (PAID) scale. The DNSs received training to interpret and discuss psychological outcomes. The computerised assessment takes 5-7 minutes and is scheduled as part of the annual review, prior to the consultation with the DNS. A report on psychological status is automatically generated and discussed with the patient. All adult outpatients with diabetes type 1 or type 2 are eligible.

Results: So far, 308 diabetes patients participated in the period between September 2005 and October 2006. Seven patients dropped out (2.1%; reasons: language problems, new patients, or second annual review), resulting in a total of 301 patients (N=301; mean age 52.3 years \pm 15.7, 50.2% male, 47.2% Type 1). Overall mean HbA1c was 7.9% \pm 1.1 (range 5.1 – 11.5%). No significant differences in HbA1c were found in sex nor in type of diabetes. Seventy patients (23.3%) reported poor well-being (WHO-5 score \leq 50), and 23 patients (7.6%) had scores indicative for depression (WHO-5 score \leq 28). Fifty-nine patients (19.6%) reported seriously elevated diabetes distress (PAID \geq 40). WHO-5 and PAID showed a significant but moderate correlation ($r = -.457$, $p < .01$). In total, 32 patients (10.6%) had high diabetes-specific distress and low emotional well-being, while 14 patients (4.7%) had high diabetes-specific distress and likely depression. Psychological functioning was not significantly associated with HbA1c. Patients who indicated low well-being and/or high diabetes-distress did not have significantly higher (or lower) HbA1c's. From WHO-5/PAID scores, 14 'cases' (4.7%) were identified, of whom 2 patients were already known and had received psychological support prior to the assessment. Nine patients were referred for professional psychological treatment as a result of the monitoring. Four of them had not (yet) agreed to psychological counselling although they had high depression and distress scores.

Conclusions: Monitoring well-being as part of ongoing diabetes care is feasible and well appreciated by both health care professionals as well as patients. It provides valuable information on patient's psychological status. Approximately 1 in 4 patients has (serious) psychological issues, warranting attention. Glycaemic control is not a good marker for psychological functioning, underscoring the need to assess well-being next to clinical parameters. An international collaborative study (DAWN MIND) has just started to promote further dissemination of this procedure in secondary care.

Title: Impact of insulin pump therapy on the quality of life of children (and their parents) using an adaptation of the SEIQoL interview

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Aims: To assess the impact of insulin pump therapy on the quality of life (QoL) of children with Type 1 diabetes and their parents.

Methods and participants: The Schedule for the Evaluation of Individualised Quality of Life (SEIQoL) interview was adapted to be (1) insulin pump-specific, (2) suitable for children (aged up to 18 years) and their parents, (3) suitable for telephone administration. Interviews were conducted to elicit the five most important aspects of life for children/parents and to identify the impact of pump therapy on those aspects and overall QoL. Separate telephone interviews were conducted with children and their parents. All children (and their parents) registered on the Roche Diagnostics insulin pump user customer database were invited to participate in the study. Due to database limitations, it is unclear how many participants met the inclusion criteria (i.e. aged 18 years or younger).

Results: Fifteen children and 17 parents participated. Children were aged 9-17 years (mean 12.07±2.71 years). Duration of diabetes ranged from 2-12 years (mean 6.67±2.42 years). For interview duration, there was no significant difference between parents and children ($p=0.281$). All parents reported the impact of their children's insulin pump therapy on their own overall QoL to be positive (47.1% ($n=8$) very much better, 35.3% ($n=6$) much better and 17.6% ($n=3$) better). Fourteen children answered this question and all responses were positive (26.7% ($n=4$) very much better, 53.3% ($n=8$) much better and 13.3% ($n=2$) better).

For parents, the most frequently reported aspects of life important for their QoL were "health" ($n=16$) and "family" ($n=11$), whilst children most frequently reported "family" ($n=12$), "friends" ($n=11$) and "school" ($n=10$). Following the initiation of their child's pump therapy, parents rated their own "health" as very much better ($n=9$), much better ($n=3$) and better ($n=4$), and rated "family" as very much better ($n=7$), much better ($n=3$) and better ($n=1$). Health was rated as most important by only 6 of the 17 (35%) parents. Four parents reported a reduction in their stress levels that they attributed to pump therapy and five reported less disruption to their worklife from repeated telephone interruptions and being called out to administer injections or deal with hypos/hypers.

For children, pump therapy had made "family" life very much better ($n=2$), much better ($n=4$) better ($n=4$) or no difference ($n=2$). Only seven children (46%) listed "health" as one of their five life domains, with none rating it as the most important aspect of life for QoL.

Discussion: All children and their parents reported the impact of pump therapy on their QoL to have been positive. One third of parents reported "health" as most important for QoL but none of the children did so. Consistent with the literature, children most frequently reported family, friends and school as important for QoL. The results of this study support the view that health cannot be regarded as the major QoL priority for children using pump therapy. Furthermore, parents perceive many benefits of importance for their own QoL from their child(ren) using insulin pump therapy.

Title: How illness representations and self-efficacy effect self-care behaviour: is there a difference between zhe experiences of individuals with type 1 andtype 2 diabetes?

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Institute: The Open University

Aims: This study investigated the different personal experiences of people with Type 1 and Type 2 diabetes and the impact of this experience on illness representations, levels of self-efficacy and self-care behaviour, using Leventhal's Commonsense Model for the Self-Regulation of Health and Illness.

Methods and participants: Participants (Type 1, n = 44, Type 2, n = 57) completed the Illness Perception Questionnaire–Revised, Summary of Diabetes Self-Care Activities Scale, Self-Efficacy Scale and a diabetes complications checklist. HbA1c results were also obtained. Semi-structured interviews were conducted with 11 participants. Interviewees were selected by type of diabetes, gender and level of self-care behaviour.

Participants were approached at their normal clinic appointment at the diabetes outpatient clinic at Milton Keynes General Hospital. They were aged between 30 and 55, had all had diabetes for at least one year and were Caucasian. A sub-set of the participants who completed the questionnaires were approached for interview. All of these interviewees were treated with insulin.

Results: Significant differences were found between participants with Type 1, tablet treated Type 2 and insulin treated Type 2 diabetes for feeling personally responsible for causing diabetes, understanding of their condition and blood testing behaviour. Significant differences were also found between different durations of diabetes for self-efficacy beliefs about looking after diabetes in a flexible way. Different relationships were found between illness representations, self-efficacy and self-care for type of diabetes and gender. Interviewees' illness representations, such as consequences of diabetes, and self-efficacy were found to have a significant effect on their performance of self-care behaviours. Interview analysis supported the differences found between type of diabetes and gender in the questionnaire analysis.

Conclusions: Type of diabetes, duration of diabetes and gender had an impact on the illness representations, self-efficacy and self-care behaviour of the participants. Illness representations and self-efficacy were shown to be associated with self-care behaviour. The variance in self-care behaviour explained in the questionnaire analysis was low; however, the interview analysis suggested that aspects of the CSM, such as socio-cultural context and the self-system, which were not measured by the questionnaires, may explain more variation in self-care behaviour.

Title: The development of alternative modes of data collection in South Asians with Type 2 diabetes

Authors: Lloyd CE, Johnson M, Mughal S, Sturt J, Collins G and Barnett AH.

Institute: The Open University

Research has shown it is difficult to recruit and collect information from individuals whose main language is spoken and does not have an agreed written form. This is a particular problem in some of the South Asian communities in the UK, a population with an increased risk of developing diabetes. The aim of this study was to develop novel ways (or a gold standard method) of administering and collecting reliable and valid data in people with Type 2 diabetes from minority ethnic backgrounds (specifically Urdu, Mirpuri, Bengali and Sylheti speakers). The particular objectives of this study were to:

- a) Develop two culturally sensitive and equivalent questionnaires - the Diabetes Management Self-Efficacy Scale (DMSES) and the Revised Diabetes Knowledge Scale (RDKS) - for use as self-management monitoring tools in people with Type 2 diabetes from minority ethnic backgrounds.
- b) Compare different modes of instrument administration and identify the most appropriate method for each language group
- c) Make recommendations with regards the use of the DMSES and the RDKS in minority ethnic populations so that these two questionnaires can then be validated in a larger sample of people from the four language groups.

Adults with Type 2 diabetes were recruited via the hospital diabetes centre and invited to attend focus groups to consider the content and mode of delivery of the two questionnaires. Individual participants took part in up to 5 focus group sessions, each focussing on a different aspect of the data collection process:

Focus Group 1: an examination of the cultural equivalence of the RDKS,

Focus Group 2: an exploration of the cultural equivalence of the DMSES,

FocusGroup 3: exploration of remaining issues and initial testing out of the audio version of the questionnaires, with a view to making any final alterations,

Focus groups 4 and 5: testing out the following modes of data collection:

1. Standard self-complete questionnaires, in the most appropriate language, using traditional paper and pencil methods.
2. Standard assisted collection: questions read out by the researcher and answered by the participant with the researcher completing the questionnaire for them.
3. Colour-coded assisted collection: one-to-one collection, with questions read out by a researcher and answered by the participant using a colour coded scoring system.
4. Independent audio collection: participant listening to an audio recording of questions in the appropriate language, and responding independently using the colour-coded scoring system.

The study was conducted by two researchers, one male Bengali/Sylheti speaker and one female Urdu/Mirpuri speaker. Informed consent to this study was obtained using audio methods which were found to be acceptable by all participants. Different reactions to and considerations of a range of issues were observed between the two main groups of participants: those whose main language was Mirpuri and those who spoke mainly Sylheti. Data is currently being analysed, the results of which will be presented at PSAD 2007.

Title: Depressive disorders, diabetic foot ulcers and death: a population-based prospective cohort study of people with diabetes and their first foot ulcer

Authors: Winkley K., Stahl D., Chalder T., Edmonds M., Ismail K.

Institute: Institute of Psychiatry, King's College London

Aim: The outcome for people with diabetic foot ulcers is very poor despite intensive medical regimens. We tested whether depressive disorders increased mortality and morbidity in people with diabetes and their first foot ulcer over 18 months.

Methods and patients: We recruited a population cohort of people who had developed their first diabetic foot ulcer in South London, United Kingdom. We used the Schedule for Clinical Assessment in Neuropsychiatry 2.1 interview to generate Diagnostic and Statistical Manual for Mental Disorders–IV (DSM-IV) major depressive disorder at baseline. During the 18 month follow up we measured the number of deaths, the time taken to die, first amputation and first recurrence of ulceration. We measured potential confounders at baseline such as age, sex, marital status, social class, smoking, glycosylated haemoglobin (HbA1c), and severity of the reference ulcer.

Results: 253 people with their first diabetic foot ulcer were recruited. The prevalence of DSM-IV depressive disorder was 24.1% (n=61). There were 40 (15.8%) deaths (all from natural causes), 36 (15.5%) amputations, and 99 (43.2%) recurrences at 18 months. 18 months later in the adjusted Cox regression analysis, DSM-IV depressive disorder was associated with a two-fold increased risk of mortality (hazards ratio 2.17, 95% confidence interval 1.12 to 4.18); but not with amputation (hazards ratio 1.72, 95% confidence interval 0.85 to 3.48), or recurrent ulceration (hazards ratio 1.18, 95% confidence interval 0.73 to 1.90); and there was no association with HbA1c ($F(1,170) = 0.55, p = 0.46$).

Conclusions/discussion: Depressive disorders, which is a treatable condition, are common and associated with an increased risk of mortality in people with their first diabetic foot ulcer.

Title: Psychological and medical intervention with diabetic children

Authors: Bregani P.

Institute: H San Raffaele

Aims: Due to parents' therapeutic control of diabetes, in diabetic children dependence on parents is more marked than in non diabetics of the same ages. This marked dependence on parents is responsible for their being often delayed or inhibited in the evolutionary processes towards autonomy and socialization. The aim of this program is to help them to improve in these areas and to cope better with diabetes,

Methods: The sample is a group from six to eight diabetics aged between eight and nine years ,of both genders. Eight session are dedicated to art therapy studied to stimulate and bring to light children's natural latent urge to progress in their psychological development acquiring the necessary skills. Two sessions are dedicated to doctor – child relationship and medical information. In the first of these last sessions a doctor and the children meet under unusual circumstance which make the children feel at ease: they all wear masks representing characters of popular T V cartoons. The doctor through the mask answers questions about diabetes that the children ask him. In the second of these sessions doctor and children , without disguises, discuss again some topics the children suggest.

Planned analysis: Parents fill in questionnaires investigating children's behaviours regarding socialization and emancipation from family as well as their active participation in diabetes therapeutic control. The results of the questionnaires before and after the program are compared.

Expected outcomes: Improvement in autonomy and in socialization processes, in the children's relationship with the doctor and in their control of diabetes.

Problems: We wonder whether the last session of the program could be more effective and could give children an exhaustive information about diabetes. What procedure could be used for this purpose?

Title: Type 2 diabetes in the family: will awareness raising and stimulating family communication be worthwhile within the framework of primary prevention?

Authors: van Esch S.C.M.^{1,3}, Snoek F.J.^{1,3}, Cornel M.C.^{2,3}

Institute: Department of Health Psychology, Utrecht University, Netherlands

¹ Dept. of Medical Psychology, Diabetes Psychology Research Group

² Dept. of Clinical Genetics, Community Genetics Research Group

³ Institute for Research in Extramural Medicine (EMGO)

Aims: With the increasing number of people with type 2 diabetes in the future, it is necessary to take preventive actions, especially directed at those most at risk. Family history may serve as a good predictor of type 2 diabetes risk. A family history reflects inherited genetic susceptibilities as well as shared environmental, cultural, and behavioural factors.

In our research project, we investigate knowledge, perceptions and ideas of people with type 2 diabetes, their close relatives, and diabetes professionals on increased susceptibility to type 2 diabetes and possibilities of primary prevention. In this presentation, however, we will focus on the knowledge and ideas of diabetes professionals. We wonder whether the familial character of diabetes is an issue in regular diabetes care, and we are interested in ideas/intentions of professionals regarding the use of family history as a potential tool in primary prevention.

Design/methods: Diabetes professionals (N=200), e.g. physicians, general practitioners, nurses specialised in diabetes, and dieticians are invited to participate in an online email survey. In focus group sessions ideas and practical implications regarding informing patients on inheritance and primary prevention will be explored in more detail. Also patients' (N=600) and family members' (N=400) need for information and coaching will be examined using questionnaires, focus group sessions and in-depth interviews. Ideas and perceptions from both sides (i.e. 'providers' and 'receivers' of information) will be compared and evaluated.

Planned Analysis: Quantitative data will be analysed using SPSS 12.0. Univariate as well as multivariate logistic regression analyses will be accomplished. Qualitative data will be analysed using Atlas.ti 5.2 (a package for analysis of large bodies of material which cannot be analyzed by formalized, statistical approaches).

Expected outcomes: On the basis of literature research, results of a published Internet review on the public availability of information on the familial character of type 2 diabetes and possibilities of primary prevention, and a pilot study among people with type 2 diabetes, we expect little knowledge on diabetes and inheritance and a minor proactive attitude of diabetes professionals in regular diabetes care.

Problems/questions to discuss: After an interactive intermezzo with the audience, we will discuss ideas regarding informing patients and people at risk on the familial character of type 2 diabetes. We will explore pros and cons, taking into account: limitations and possibilities of public campaigns vs. routine (diabetes) care; ethical & psychological implications for patients and relatives; ethnic susceptibility leading to different approaches addressing different groups; concepts of guilt, responsibility, and duty to inform.

Title: Monitoring health-related quality of life in adolescents with type 1 diabetes. baseline and preliminary follow-up results

Authors: de Wit M., Delemarre-van de Waal H.A., Gemke R.J.B.J., Snoek F.J.

Institute: VU University medical center Amsterdam

Aims: Systematic monitoring of psychosocial functioning in adolescents with diabetes may help to improve physical and psychosocial well-being and glycaemic control. In an ongoing RCT, we investigate the effects of monitoring of HRQoL on physical and psychosocial well-being, HbA1c and satisfaction with care in adolescents with diabetes.

Design/Methods: Four outpatient paediatric diabetes clinics in the Netherlands were randomized over either care as usual or monitoring condition, a 3-monthly computerized HRQoL assessment (using the PedsQL) and discussion of outcomes with the paediatrician or nurse. Demographic, medical and psychosocial data were gathered at baseline and follow-up (12 months). 91 patients completed the Child Health Questionnaire-Child Form 87 (CHQ-CF87), Center for Epidemiological Studies Depression scale (CES-D), Diabetes-related Family Conflict Scale (DFCS) and the Patients' Evaluation of the Quality in Diabetes Care (PEQ-D). Parents completed the CHQ-PF50, CES-D, DFCS and PEQ-D.

Planned analyses: At baseline, mean age was 14.9 years, mean HbA1c 8.8% (\pm 1.7; 6.2-15.0%). Compared to healthy controls, patients scored only lower on CHQ subscales role/social-physical limitations and general health. 3.3% of the patients had scores indicating moderate to severe depression. Adolescents only rated their behaviour more positive than their parents did. Less Diabetes-related Family Conflict was related with better psychosocial health and less depressive symptoms. Living in a one-parent family, not being Caucasian and reporting more limitations in social interactions due to behavioural problems are associated with higher HbA1c values at baseline. The effect of the intervention will be analysed at follow-up by repeated measures analysis. Predictors of HbA1c and well-being will be tested by linear regression analyses. Structured interviews will be conducted to get better insight in the appreciation of the procedure by adolescents and paediatricians.

Expected outcomes: Overall, our adolescents report to do well at baseline and this coincides with parent report. Poor glycaemic control is common, with single-parent and non-Caucasian families particularly at risk. High HbA1c values are related to low social and family functioning. As for the intervention, we expect little improvement in physical and psychosocial well-being, because of ceiling effects at baseline. It is hard to establish long-term decrease in HbA1c values in adolescents, but discussing family conflicts and lower well-being could result in better glycaemic control and better family functioning.

Problems/questions to discuss: To what extent are parent reports valuable for predicting adolescents' well-being and glycaemic control?

Title: On-Line: Web-based cognitive behavioural therapy (CBT) for diabetic adults with minor to moderately severe depression. A randomised controlled trial.

Authors: van Bastelaar K.M.P., Pouwer F., Cuijpers P., Snoek F.J.

Institute: VU University Medical Centre, Amsterdam

Aims: This study aims to test the effectiveness and appreciation of a 12-week web-based cognitive behavioural therapy (CBT) program for adult diabetic persons with minor to moderately severe depression in a randomized controlled trial.

Design and methods: The recruitment occurs via www.diabetergestemd.nl and (mental) health care institutes. Patients are invited to fill-out online: demographic data, diabetes and depressive symptoms. If a patient is eligible to participate in the study, a telephone interview (15 minutes) is done to confirm minor to moderately severe depression. Patients –by means of randomisation– assigned to the intervention group start the 12-week web-based cognitive behavioural therapy (CBT) program. The control group is placed on a waiting list, and switched to the intervention group after 4 months. The effectiveness of the interventions is determined directly after completion of the intervention, at 1 and at 3 months follow-up. Primary outcome measures are depressive symptoms (CES-D) and diabetes-related emotional distress (PAID). Secondary outcome measures are: Satisfaction with the program, Perceived Health Status, Diabetes self-care, Glycaemic control (HbA1c, hypo's and DKA's), Mental health care consumption, and health outcome.

Planned analysis: By means of t-tests and chi-square tests, baseline variables will be compared for the intervention and control group. ANOVA's will be performed with the CES-D and PAID as dependent variable, with two independent variables: time (within-subject) and group (between-subject). ANCOVA's will be performed in order to test whether both groups have different scores on the CES-D and the PAID, at different points in time, with correction for potential confounders at baseline. Regression analysis will be performed, taking into account the correlational nature of repeated measures within subjects, and securing minimal loss of patients due to incomplete data. Clinical effectiveness will be calculated with effect size calculation using Cohen's d.

Expected outcomes: It is hypothesized, that on-line CBT will be well-received by the participants. The intervention condition is expected to be significantly more effective than the control condition in reducing depressed mood and diabetes-related emotional distress, with subsequent positive effects on self-management behaviours and glycaemic control.

Problems/questions to discuss::

- Which strategies are available to maximize the reach of our intervention?
- Drop out is a known problem in web-based therapy. Which strategies are available to reduce the amount of drop-out?

Title: A multi-constituency study of access to diabetes education in the USA

Authors: Peyrot M.

Institute: Loyola College

Aims: To understand why only one-third to one-half of people with diabetes in the USA receive diabetes self-management education

Design and methods: The study has 2 phases: focus groups (completed) and internet surveys (in planning stage). There are 3 independent study populations: Physicians, diabetes educators, people with diabetes.

Planned analysis: Focus group data received qualitative analysis. Survey data will be analyzed statistically. Analysis of patient data will assess associations of the outcome of not receiving education with risk factors, including physician behaviour, attitudes toward diabetes education, financial/logistical resources/barriers, etc. Analysis of physician data will assess associations of the outcome of not referring patients for education with risk factors, including attitudes toward diabetes education, patient case-mix, availability of diabetes education resources, etc. Analysis of educator data will assess strategies for increasing patient access to education, including past efforts and willingness to utilize alternative delivery strategies.

Expected outcomes: Identify factors that can be targeted to increase access to and receipt of diabetes self-management education

Problems/questions to discuss:

- What are the key questions to be asked in the surveys?
- What are the potential sources of bias, and how can they be overcome?

Title: Cell transplantation in people with type 1 diabetes: psychological outcome at 12 months post-transplantation

Authors: Hendrieckx C.

Institute: Diabetes Research Center – Vrije Universiteit Brussel

Aims: To evaluate the psychological impact of cell transplantation in patients with and without graft function 12 months post transplantation.

Methods and patients: Patients with type 1 diabetes taking part in a clinical trial of cell transplantation were invited to complete questionnaires at the time of screening and at 3, 6 and 12 months post transplantation. Preliminary results on month 3 and 6 have been presented at the PSAD 2004. Today 24 patients have past the 12 months follow-up of which 11 have a functioning graft. Participants completed the SF-36 and the Diabetes Treatment Satisfaction Questionnaire (DTSQ). A subsample of 16 patients completed the Problem Areas in Diabetes (PAID) Scale. Baseline scores on all measures were compared with scores at months 12. Data were analysed using non-parametric tests for 2 related samples.

Results: Compared to baseline, patients with graft function reported less episodes of hypo- and hyperglycemia (DTSQ), and improved general health (SF-36). They scored lower on the mental health and vitality scales (SF-36) compared to pre-transplantation.

Those without graft function also reported less episodes of hypoglycemia. For this group no other changes were measured between the two time points.

Conclusions/discussion: Although there is a positive impact of a functioning graft on diabetes control it is not translated into improved well-being or decreased psychological distress. This is due to the side effects of the anti-rejection medication. It is currently known that metabolic control after cell transplantation declines over time which creates uncertainty about the long-term benefit of the graft. Clinical implications of these results will be discussed.

Title: Brain activation and its relationship to psychobiosocial factors affecting dietary self-care in type 2 diabetes

Authors: Chechlacz M., Rotshtein P., Nouwen A.

Institute: University of Birmingham, Birmingham, UK

Successful modifications in eating habits according to dietary self-care recommendations for type 2 diabetes (t2D) are thought to reduce the risk of diabetes-related complications. Yet, many patients with t2D have difficulty following these recommendations and those who do often report feeling 'restricted' in their food choices.

Motivational constructs (e.g., self-efficacy) and social influences (perceived support) are associated with successful adherence to dietary self-care recommendations. In a pilot study using fMRI technique, we found that adherence to a diet might be related to responses in gustatory (insula) and emotion/motivation-related regions such as the amygdala and OFC.

To further our understanding of the processing involved in response to gustatory stimuli disrupting or facilitating dietary adherence we propose a follow up study to investigate how t2D condition modulates perceptual sensitivity to gustatory stimuli and whether emotional/social factors influence these effects.

Proposed design and methods: 1) to test implicit and explicit perception of low and high calorie foods as measured using reaction times, autonomic responses and fMRI; 2) to examine whether these effects are modulated by an emotional/social context. We propose to use facial expressions as primes, which will appear immediately preceding the food pictures to address a question whether different expressions have differential effects on processing of high vs. low calorie food stimuli and whether these effects would be modulated by the social context experienced by t2D patients (i.e. the interactions with spouses and family members).

Questions proposed for the group discussion: 1) What is the best way to manipulate the social context, i.e. what type of expressions to use: disgust vs. liking or approval vs. disapproval? 2) Is it important that the expression would be presented by a socially relevant figure or not? 3) What would be the most relevant control group e.g. would it be relevant to include a different control group that would allow a comparison between disease related and voluntary diet?

Title: Life skills with diabetes in transition from youth to adulthood. Guided self-determination for young people with type 1 diabetes and their parents

Authors: Zoffmann V.

Institute: UCSF (University hospitals' Centre for Nursing and care research) Copenhagen, Steno Diabetes Center, Glostrup Hospital and Hillerød Sygehus

Aims: To develop a version of Guided Self-Determination adjusted to young people with type 1 diabetes and their parents (GSD-youth) and test if the method promotes life skills including good glycemic control in the transition from youth to adulthood.

Design and methods: The research will be conducted in 3 phases:

1. Participatory research is currently being conducted together with three diabetes teams at Danish university hospitals in order to develop an applicable and acceptable version of GSD-youth adjusted to the needs of young people (12 – 22years) with type 1 diabetes and their parents. GSD-youth involves reflection sheets filled in by the patient and each parent individually as well as by siblings if relevant. The filled in sheets will be used by health care providers in dialogues with patient and family in order to support the patient and the family in developing life skills with type 1 diabetes.
2. Qualitative evaluation will be conducted in (2008-2010) order to evaluate in detail the ability of GSD-youth to change communicative patterns in families when used by young people with type 1 diabetes and their parents in individual training. The study will describe the ability of families to communicate and solve conflicts, make decisions and identify, pose and solve problems related to type 1 diabetes with or without GSD-youth. (Ph.d. study)
3. Randomised controlled trial is conducted in (2009-2010) to test the effect of group-based GSD-youth. Measurements will be chosen in accordance with qualitative findings.

Differences within and between groups will be measured ½ year, 1 year and 2 years after training.

Planned analysis: see above and below

Expected outcomes (of RCT): increases are expected in the autonomy support perceived by patients from parents and professionals, in the diabetes patients' autonomous motivation for self-management of diabetes, (part of their life skills with diabetes) and in numbers of self-monitored blood glucoses. Decreases are expected in A1c, in problems related to diabetes and in frequency of cancelling or failure of showing-up in the diabetes clinic.

Problems/questions to discuss: I will like to discuss phase 3 and the possible scales available for youth in the randomised study in order to measure the expected outcomes.

[1] Life skills are those personal, social, cognitive and physical skills which enable people to control and direct their lives, and to develop the capacity to live with and produce change in their environment.