Psychological Care and Support Needs: What do People with Diabetes and their Caregivers say?

Preliminary Results from “Life with Diabetes 2019”, a National Danish Diabetes Survey

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Background

Despite significant developments in the field of diabetes psychology, large scale research into the perspectives, wishes, and preferences of people with diabetes (PWD) and their caregivers (CG) about 1) how to best improve psychological monitoring, care and support and 2) how to measure progress is lacking.

Aims

To obtain nationwide insights about the experiences of PWD and CG regarding

1) Access to person-centered diabetes care incl. psychological care & support.
2) Diabetes related health & wellbeing
3) Priorities, preferences and wishes for improvement of care in Denmark.

To initiate the first nationwide scientific survey, “Life with Diabetes” for annual monitoring of PWD/CG reported quality of diabetes care and support in Denmark.

Methods

Survey questionnaires (40-50 items) for PWD and CG of PWD and parents of children with diabetes were designed through a participatory process. Items were newly designed or pre-validated. Key items from the Danish PRO diabetes program1 were included. A mixed-method qualitative research study design was embedded. 38.820 members of the Danish Diabetes Association were invited by mail using SurveyXact. Software: SPSS-20/Nvivo-12.

Implications – next steps

- Statistical and qualitative analyses are ongoing to detail care and quality of life gaps, wishes and inputs from PWD & CG to inform policy and care action for better diabetes care in Denmark.
- Insights are applied by the national PRO diabetes program to improve psychological monitoring & follow-up.
- PWD and CG should be involved as collaborators also at population level to improve psychosocial diabetes care.

Results (1)

9.108 adult PWD (761 CG of adults, 296 parents of CWD) completed the survey. 71% had type 2, 26% type 1 diabetes. 51% were women. Respondents were well represented from all regions of Denmark. Initial data review indicate respondents were comparable to the general Danish population for age and gender but had longer education (only initial descriptive data reported here). 1.100 free text inputs about care gaps and priorities were obtained for coding and mixed-method qualitative research.

Results (2)

"Have you been offered a referral to a psychologist in connection with your diabetes care?"

Results (3)

Do you get the support you need for dealing with potential psychological challenges (PWD) / thoughts & emotions (CG) related to diabetes?

Conclusions

In our survey of >10.000 PWD and CG
- One in five of PWD and CG of PWD reported lack of psychological care and having very frequent diabetes worries.
- Those reporting poor daily life with diabetes* had greater need for referral.
- Improvement in psychosocial support is a key priority for many PWD and CG.

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References


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