Development of a National Minimal Set of Patient-Important Outcome Domains for Value-Based Diabetes Care in Denmark

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Background

- The cross-regional project for Value Based Health Care (VBHC) in Diabetes in Denmark, VBHC PRO-DIA, is sponsored by Northern Region Bentheim and Aalborg University Hospital in partnership with the Danish Diabetes Association and Aalborg University.

- The aim is to develop and evaluate solutions for value-based diabetes care in Denmark under the heading: Improving care by better understanding nutritional and multi- disciplinary action to improve care through a clinical and analytical solution designed around a shared definition of "patient value".

- The first step presented here was to establish a minimal set of patient-important outcome domains, incl. PRO, to assess "value".

Method (1) Qualitative methodology

- Qualitative research as part of evidence-guided quality patient engagement (PPMD, NHI 2018 using 7 criteria: Shared purpose, respect, responsibility, representativeness, capacity/capability, documentation and sustainability.

- Individual semi-structured interviews and workshops were undertaken with 24 persons with diabetes and caregivers.

Method (2) Qualitative methodology

- Semi-structured interviews: Participants completed open-ended questions individually or in groups. Open-ended questions were also asked. Focus group and workshops: Four focus groups and workshops consisting of focus group, consensus and co-creation sessions (see agenda below).

- Qualitative analysis: Individual responses and group process outputs were analysed and coded separately.

- Group avenues, findings and final report taking into account group dynamics, differences and analysis of common denominators.

- Core outcomes were included from our care planning generating purposes. The results for caregivers will be presented elsewhere.

Method (3) Patient workshop agenda

- Introduction and welcome by local patient organisation and facilitator.
- Share experiences and stories among peers.
- How do diabetes affect your psychosocial and psychological wellbeing?
- What are your most important challenges you face in your everyday life?
- How do diabetes affect your self-esteem?
- What are the consequences of your diabetes?
- What are the consequences of your diabetes?

Results (1) Participants

<table>
<thead>
<tr>
<th>Category</th>
<th>Type 1</th>
<th>Type 2</th>
<th>Content</th>
</tr>
</thead>
<tbody>
<tr>
<td>Blood sugar control</td>
<td>A1c, BGM, CGM</td>
<td>-</td>
<td>Diabetes in Denmark, VBS PRO-DIA</td>
</tr>
<tr>
<td>Psychological well-being and risk of depression</td>
<td>-</td>
<td>-</td>
<td>Diabetes in Denmark, VBS PRO-DIA</td>
</tr>
<tr>
<td>Somatic diabetes symptom distress</td>
<td>-</td>
<td>-</td>
<td>Diabetes in Denmark, VBS PRO-DIA</td>
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<tr>
<td>Multi-tasked impact of diabetes on life</td>
<td>-</td>
<td>-</td>
<td>Diabetes in Denmark, VBS PRO-DIA</td>
</tr>
</tbody>
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Aims of the qualitative research

- Inform selection of a minimal set of patient-important diabetes outcome domains for VHIC by the median list of patient-important and multi-disciplinary workshop group (incl. PwD).

- Use the VBHC framework (Porter et al. 2010, specific aims was to gain perspective of PwD and caregivers on: 1. Your personal experience of diabetes (experiences, symptoms, impact of diabetes). 2. Healthcare and treatment (modality, duration, accessibility). 3. Diabetes treatment (modality, duration, accessibility) 4. Factors affecting sustainability. 5. Qualitative feedback was contextualized by supportive research in line with evidence-guided patient partnering methodology.

- Develop a National Minimal Set of Patient-Important Outcome Domains for Value-Based Diabetes Care in Denmark

Method (4) PRO outcomes domains

- Self-reported health status (general)
- Psychological well-being and risk of depression (general)
- Somatic diabetes symptom distress (incl. nevrapathy, pain, hypertension, complications)
- Multi-tasked impact of diabetes on life (incl. social relations, family, work/study, leisure, quality of life)

Conclusions and next steps

- Qualitative research and partnering with PwD informed national multi-stakeholder expert decision process regarding relevance of PRO-based outcome domains for outcomes assessment in value-based diabetes care.

- Domains were supported by follow-up patient workshops, survey research in collaboration with ICKOM, and by literature review of multi-national qualitative and survey research (Nicolaou, Stucky, Young, Fyrman).

- Next phases now are to further detail domains, finalise PRO national questionnaires, develop and test final VHIC PRO diabetes care solution in Northern Region of Denmark and with collaborating regions/silos.

- Our research supports use of our clinically anchored evidence-guided PwD partnering process for all steps of PRO implementation, including term selection, linking PwD to care actions and considering vulnerable groups.

- PwD item bank and branching technology is applied to address population heterogeneity and cross-racial-outcome.

- International collaboration for harmonisation of PRO diabetes methods is likely to have future nitro PRO efforts.

Acknowledgements

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References