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Svar från SBU:s upplysningstjänst nr ut201905 • Diarienummer: SBU 2018/47 • Datum: 2019-03-08

Strukturerad övergång från barn- till vuxendiabetesvård för unga med typ 1-diabetes

Flertalet unga och vuxna i åldersgruppen 15–25 år med typ 1-diabetes har dålig glykemisk kontroll, vilken medför risk för svåra långsiktiga komplikationer. En strukturerad övergång från barn- till vuxendiabetesvård för unga vuxna med typ 1 diabetes skulle kunna bidra till en förbättrad blodsockerkontroll.

Fråga

Vilken effekt har en strukturerad transitionsvård mellan barn- och vuxendiabetesvård för unga med diabetes typ 1?

Frågeställare: Överläkare Barndiabetesteam, Västra Götalandsregionen

Sammanfattning

SBU:s upplysningstjänst har identifierat nio systematiska översikter som sammanställer forskning som finns om strukturerad transitionsvård för unga personer med typ 1-diabetes, samt för unga personer med andra kroniska tillstånd. I flera av de systematiska översikter som identifierats drar författarna slutsatsen att strukturerad transitionsvård kan ha positiva effekter på bland annat glykemisk kontroll och anpassningen till vuxenvård. Underlagen i översikterna var övervägande observationsstudier och deskriptiva studier, mycket få randomiserade kontrollerade studier finns på området. Översikterna belyste även vilka faktorer som bedöms viktiga för en framgångsrik övergång från barn- till vuxenvård.

SBU har inte tagit ställning i sakfrågan eftersom vi inte har bedömt de enskilda studiernas kvalitet eller vägt samman resultaten. Här redovisar vi därför endast de enskilda författarnas slutsatser.

Bakgrund

Övergången från barndiabetesvård till vuxendiabetesvård innebär strukturella förändringar och kan vara en svår process för individen. För unga vuxna medför det en omställning där individen ska gå från att som barn ha utfört egenvård under förälders handledning till att på ett självständigt sätt hantera egenvård och sjukvårdskontakter. Denna övergångsperiod innebär en särskild medicinsk utsatthet, där en längre tidsperiod mellan barndiabetesvård och rutinmässig vuxendiabetesvård medför en större risk för sämre glykemisk kontroll och komplikationsutveckling [1]. Personer i åldern 15–25 år med typ 1-diabetes är den åldersgrupp med diabetes som har högst HbA_{1c}, vilket har en koppling till högre komplikationsrisk. Optimal övergång från barn- till vuxenvård är viktigt vid flera kroniska tillstånd (t.ex. inflammatorisk tarmsjukdom, cystisk fibros, medfödda hjärtfel m.fl.). Området strukturerad transitionsvård benämns i internationell litteratur som ”transition of care” eller ”transition medicine” [2].

Avgränsningar

Vi sökte på interventionen ”transition of care” (strukturerad transitionsvård) generellt, oavsett population (se avsnittet Litteratursökning). Vi avgränsade sökningen till systematiska översikter, HTA-rapporter och riktlinjer. Sökningar gjordes i databaserna PubMed, CINAHL, Cochrane, och CRD. Sökningarna avgränsades till artiklar skrivna på engelska, danska, norska och svenska. Vi har avgränsat svaret till systematiska översikter från år 2014 och framåt. Detta beror på att de två randomiserade kontrollerade studier som identifieras i översikterna var från år 2014 och år 2015 och äldre systematiska översikter därmed inte är lika uppdaterade.

Resultat från sökningen

Upplysningstjänstens litteratursökning genererade totalt 197 artikel-sammanfattningar (abstrakt). En projektledare på SBU läste alla artikel-sammanfattningar och bedömde att 48 kunde vara relevanta. Dessa artiklar lästes i fulltext av projektledaren. I upplysningstjänstsvaret ingår nio systematiska översikter, fem översikter gällande transitionsvård för unga med typ 1-diabetes samt fyra översikter på kroniska tillstånd generellt, där typ 1-diabetes ingick som huvudpopulation. De artiklar som inte var relevanta för frågeställningen exkluderades. Observera att varken kvaliteten på översikterna eller de inkluderade studierna bedömdes. Det är därför möjligt att flera av studierna kan ha haft lägre kvalitet än vad SBU inkluderar i sina ordinarie utvärderingar.

Systematiska översikter

Här sammanfattas de systematiska översikter som identifierats som undersökt effekten av ”transition of care” (strukturerad transitionsvård) mellan barn- och vuxendiabetesvård för unga personer (15–25 år) med typ 1-diabetes (Tabell 1). Därefter sammanfattas de systematiska översikter som inkluderat studier på unga personer med olika kroniska tillstånd, där diabetes varit en av de inkluderade delpopulationerna (Tabell 2). Inkluderade studier i dessa översikter omfattade framför allt observationsstudier och deskriptiva studier. Två randomiserade kontrollerade studier, från år 2014 och år 2015, ingår som underlag i en del av översikterna [3,4]. Inkluderade studiers studietyp i respektive översikt benämns enligt originalförfattarna.

Tabell 1. Systematiska översikter på unga personer med typ 1 diabetes
 Table 1. Systematic reviews on adolescents with diabetes type 1

Included studies	Population/intervention	Outcome
Schulz et al 2017 [5]		
18 studies, including: 1 RCT [3] 1 prospective cohort 10 retrospective cohort 6 quasi-experimental 4 studies in meta-analysis	Youth with Type 1 diabetes, (ages 11-26); Transition program from pediatric to adult care	Glycemic control Severe hypoglycemi Diabetic ketoacidosis

Authors' conclusion:

“This review suggests that transition interventions may be effective in maintaining glycemic control and/or prevent its worsening during transition. While there is a trend that programs that included both a transition coordinator and dedicated transition clinic demonstrating better glycemic improvements than those with a single component, it remains unclear which elements of transition programs are most effective at improving diabetes outcomes. Other outcomes, including number of severe hypoglycemic and DKA events, appear to improve post-transition when a transition program is in place. There may also be benefits to a later transition in care rather than an earlier one.

Currently, recommendations from professional organizations on transition interventions lack evidence and are primarily based on consensus of professional opinion. Additional research is needed to generate evidenced-based guidelines and to determine which transition elements are most effective during the transition period from pediatric to adult care. Future studies should compare transition components to assess which have greatest efficacy.”

Hynes et al 2016 [6]		
12 studies, including: 8 quantitative 4 qualitative	Young adults with Type 1 Diabetes mellitus (15–30 y); Setting: Transition (8 studies) Young adult diabetic clinic (4 studies)	Attendance Transition delay (delay in attending adult clinic)

Authors' conclusion:

“Young adult’s experiences transitioning from paediatric to adult diabetes care can influence attendance at the adult clinic positively if there is a comprehensive transition programme in place, or negatively if the two clinics do not communicate and provide adequate support. Post-transition, relationship development and perceptions of the value of attending the clinic are important for regular attendance. Controlled research is required to better understand decisions to attend or not attend outpatient services among people with chronic conditions. Service delivery must be sensitive to the developmental characteristics of young adults and tailored support may be required by young adults at greatest risk of non-attendance.”

Findley et al 2015 [7]		
31 studies, including: 18 quantitative studies 1 RCT [4] 13 qualitative studies	Adolescents with type 1 diabetes (ages 14–29); Data-based investigations that addressed health care transition, including structured transition programmes	Glycemic control, Type of post transfer practitioner (general or endocrinologist), Hospitalisations, Experiences, Elements of successful transition

Authors' conclusion:

“Key components of transitional care practices that are associated with positive outcomes are structured transitional care programs, individual support (in person or technology based), and strong relationships with providers (physicians, nurses, dieticians). In order to develop a consensus model for implementing transitional care into routine practice quality research incorporating all perspectives must be conducted and evaluated systematically. This research is essential in creating a seamless system of care for emerging adults with diabetes, to enhance individual quality of life and help to prevent long term diabetes complications and comorbidities.”

Sheehan et al 2015 [8]		
46 articles (43 studies), including: 24 studies on transition [6 controlled studies, 18 before-after studies], 24 studies on experiences	Young people with type 1 diabetes; Transition from child to adult healthcare, incl. specific transition programmes	HbA _{1c} Attendance Diabetes-related admissions (diabetic ketoacidosis) Self-care; Experiences: Discontinuity of care Renegotiation of condition management Psychological and practical needs

Authors' conclusion:

“Although the various transition processes were not well described, thus making comparability across studies difficult, there appears to be some preliminary evidence of a positive impact of structured transition programmes on glycaemic control, clinic attendance and diabetes-related hospitalizations for young people with Type 1 diabetes during healthcare transition. Studies assessing the outcomes of participants who attended transition programmes or interventions, compared with those who did not, found no change in or improved glycaemic control, better attendance rates and fewer diabetes-related hospitalizations post-transition. Well designed randomized controlled trials are now needed to assess this. It is also important that future studies provide in-depth descriptions of transition processes and protocols so that cross-study comparisons can be made. Studies examining the experiences of transition suggest many processes that should be considered in transition programmes as they are likely to improve outcomes and experiences for young people with Type 1 diabetes. These include better continuity of care, greater continuity of medical staff in adult care, more preparation for enhanced responsibility, and more communication and collaboration between child and adult services.”

Farrell et al 2014 [9]		
13 studies descriptive/ comparative	Young adults with type 1 diabetes (15–19 years) transitioned from pediatric to adult health care services. Any intervention which identified factors that influenced the transition (structured or unstructured)	Factors that determine diabetes care outcomes: Primary outcomes: Diabetes control as measured by HbA _{1c} at follow-up, loss to follow-up, adherence to insulin therapy, incidence of hospital admission for acute complications, and frequency and regularity of clinic attendance. Secondary outcomes: Uptake of screening for long term diabetes complications, cost effectiveness of intervention, health-related quality of life and patient satisfaction.

Authors' conclusion:

"The evidence identified from this review is suggestive that a structured transition intervention employing a dedicated health professional to support and coordinate the process is more likely to prevent loss to follow-up, maintain clinic attendance, have a positive impact on diabetes control, reduce hospital admissions, and be a more cost effective and positive experience for patients than an unstructured or usual care model."

Abbreviations:

HbA_{1c} - Glycated hemoglobin (hemoglobin A1c), a measure of glycemic control.

Tabell 2. Systematiska översikter över unga med olika tillstånd

Table 2. Systematic reviews over adolescents with different conditions

Included studies	Population / Intervention	Outcome
Gabriel et al 2017 [10]		
43 studies, including: 15 on diabetes type 1	Youths transferring from pediatric to adult outpatient healthcare; Transition interventions Transition interventions were analyzed in terms of: transition preparation, transfer of care, and integration into adult care	Population health outcomes: – adherence to care (incl. disease-specific outcomes) – patient-reported health – quality of life – self-care skills Experience of care: – satisfaction with care – barriers to care Utilization/ cost measures: – service utilization (incl. clinic, hospital, surgery, procedures) – process of care (incl. communications among providers, documentation of transition, clinical processes) – costs of care.

Authors' conclusion:

"Structured transition interventions often resulted in positive outcomes. Future evaluations should consider aligning with professional transition guidance; incorporating detailed intervention descriptions about transition planning, transfer, and integration into adult care; and measuring the triple aims of population health, experience, and costs of care."

Campbell et al 2016 Cochrane Review [2]		
4 RCT, including: 2 RCT diabetes type 1 [3],[4]	Adolescents with conditions requiring ongoing clinical care (incl. diabetes mellitus, cystic fibrosis, muscular dystrophy, congenital heart disease, cerebral palsy, autism, juvenile idiopathic arthritis, solid organ transplantation, and epilepsy). Transitional-care models: Any care model (or clinical pathway) aimed at improving the transition of care for adolescents from paediatric to adult health services (dedicated adolescent units, joint clinics, the use of specialised key workers).	Disease-specific patient outcomes or status: – HbA _{1c} , – lung function, – disease-specific patient-reported outcomes; Secondary outcomes: – Transitional readiness – Patient satisfaction – Treatment adherence – Health-related quality of life – Disease-related knowledge – Self-advocacy skills – Improved documentation of transitional issues – Unanticipated or adverse outcomes – Healthcare resource use and cost data

Authors' conclusion:

“The available evidence [...] covers a limited range of interventions developed to facilitate transition in a limited number of clinical conditions, with only four to 12 months follow-up. These follow-up periods may not be long enough for any changes to become apparent as transition is a lengthy process. There was evidence of improvement in patients’ knowledge of their condition in one study, and improvements in self-efficacy and confidence in another.”

“While there is a wide range of transition programmes that are being developed in different countries, often within particular clinical specialties, this review only identified four small studies that provided low certainty evidence about educational interventions targeting participating adolescents, and no studies of interventions that targeted the organisation of care (for example, joint clinics or provision of a key worker).”

Rachas et al 2016 [11]		
23 articles, including: 11 on diabetes type 1	Patients with long term health conditions requiring ongoing health care; Patient care initiated in pediatric department	Continuity of care (24 indicators); 2 main aspects: engagement retention in adult care

Authors' conclusion:

“This review highlights the paucity of knowledge about the efficacy of transition programs for ensuring care continuity during the transfer from pediatric to adult care. The outcomes identified are relevant and not specific to a disease. However, the prospective follow-up of patients initially recruited in pediatric care should be encouraged to limit an overestimation of care continuity.”

Chu et al 2015 [12]

5 studies, including: 4 on diabetes; 1 RCT [3] 3 retrospective observational	Adolescents and young adult with chronic illness; Transition intervention programs	Transfer, defined as attending at least one appointment with an adult healthcare provider
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Authors' conclusion:

“While the current evidence base to guide healthcare transfer is lacking, this systematic review's findings may provide a foundation for future research that rigorously examines the key components of effective transfer described above. Most notably, establishing clearer definitions and metrics of transfer success, creating infrastructure that facilitates measurement and tracking of patient transfers, and measuring the impact of discrete intervention components on transfer success will be important in extending the evidence base available to guide practice and ensuring that the positive effects of transition interventions are durable into adulthood.”

Abbreviations:

HbA_{1c} - Glycated hemoglobin (hemoglobin A1c), a measure of glycemic control

Lästips

Flertalet riktlinjer och stöddokument identifierades som belyste aspekterna kring transition of care. Stöddokument gällande transition of care för unga med diabetes typ 1 identifierades från NICE (The National Institute for Health and Care Excellence, UK) 2016 [13], NHS (National Health Service, UK) 2012 [14] och American Diabetes Association 2011 [15]. Stöddokument för strukturerad transitionsvård för unga med kroniska sjukdomar identifierades från NIHR (National Institute for Health Research) 2010 [16]. Generella riktlinjer för unga med diabetes identifierades från International Society for Pediatric and Adolescent Diabetes 2014 [17]. En systematisk översikt identifierades som granskat det vetenskapliga underlaget i existerande riktlinjer [18].

Projektgrupp

Detta svar är sammanställt av Malin Höistad, Maja Kärman, Sara Fundell och Miriam Entesarian Matsson vid SBU.

Litteratursökning

Medline via OvidSP 23 January 2019

Title: Transition of care from pediatric to adult services for young adults with type 1 diabetes

Search terms	Items found
Population: Diabetes mellitus hos barn, ungdomar och unga vuxna	
1. exp *DIABETES MELLITUS/	316996
2. exp *Chronic Disease/	24566
3. (diabet* or "chronic illness*" or "chronic disease*" or "chronic condition*").ti.	327126
4. 1-3 (OR)	399629
Intervention: Strukturerad överföring från barnsjukvård till vuxenvård	
5. exp transition to adult care/ or exp transitional care/	1522
6. ((transit* or transfer*) adj6 (care or healthcare or program* or clinic* or self-care or self-manag* or manag* or plan* or intervent* or service* or process* or age or adult* or adolescen*)).ab,ti	77570
7. 5 OR 6	77861
Study types: systematic reviews, meta analysis	
8. meta analysis.pt. or systematic reviews.pt.	
Limits: language	
9. danish or english or norwegian or swedish	
Combined sets	
10. 4 AND 7 AND 8 AND 9	100

The search result, usually found at the end of the documentation, forms the list of abstracts.

.ab. =Abstract

.ab,ti. = Abstract or title

.af.= All fields

Exp= Term from the Medline controlled vocabulary, including terms found below this term in the MeSH hierarchy

.sh.= Term from the Medline controlled vocabulary

.ti. = Title

/ = Term from the Medline controlled vocabulary, but does not include terms found below this term in the MeSH hierarchy

* = Focus (if found in front of a MeSH-term)

* or \$= Truncation (if found at the end of a free text term)

.mp=text, heading word, subject area node, title

Cinahl via EBSCO 23 January 2019

Title: Transition of care from pediatric to adult services for young adults with type 1 diabetes

Search terms	Items found
Population: Diabetes mellitus hos barn, ungdomar och unga vuxna	
1. (MM "Diabetes Mellitus+") OR (MM "Chronic Disease+")	119,185
2. TI (diabet* or "chronic illness*" or "chronic disease*" or "chronic condition*") OR AB (diabet* or "chronic illness*" or "chronic disease*" or "chronic condition*")	185,134
3. 1 OR 2	207,565
Intervention: Strukturerad överföring från barnsjukvård till vuxenvård	
4. (MH "Transitional Care") OR (MH "Transitional Programs")	3,377
5. TI (((transit* or transfer*) N6 (care or healthcare or program* or clinic* or self-care or self-manag* or manag* or plan* or intervent* or service* or process* or age or adult* or adolescen*))) OR AB (((transit* or transfer*) N6 (care or healthcare or program* or clinic* or self-care or self-manag* or manag* or plan* or intervent* or service* or process* or age or adult* or adolescen*)))	24,464
6. 4 OR 5	26,022
Study types: systematic reviews, meta analysis	
7. MH "Systematic Review" OR ZT "systematic review" OR MH "Meta Analysis" OR ZT "meta analysis"	110,387
8. (TI (systematic* n3 review*)) or (AB (systematic* n3 review*)) or (TI (systematic* n3 bibliographic*)) or (AB (systematic* n3 bibliographic*)) or (TI (systematic* n3 literature)) or (AB (systematic* n3 literature)) or (TI (comprehensive* n3 literature)) or (AB (comprehensive* n3 literature)) or (TI (comprehensive* n3 bibliographic*)) or (AB (comprehensive* n3 bibliographic*)) or (TI (integrative n3 review)) or (AB (integrative n3 review)) or (JN "Cochrane Database of Systematic Reviews") or (TI (information n2 synthesis)) or (TI (data n2 synthesis)) or (AB (information n2 synthesis)) or (AB (data n2 synthesis)) or (TI (data n2 extract*)) or (AB (data n2 extract*)) or (TI (medline or pubmed or psyclit or cinahl or (psycinfo not "psycinfo database") or "web of science" or scopus or embase)) or (AB (medline or pubmed or psyclit or cinahl or (psycinfo not "psycinfo database") or "web of science" or scopus or embase)) or (TI (meta-analy* or metaanaly*)) or (AB (meta-analy* or metaanaly*))	140,478
9. 7 OR 8	171,744
Limits: language	
10. Narrow by Language: - english	
Combined sets	
11 3 AND 6 AND 9 AND 10	112

The search result, usually found at the end of the documentation, forms the list of abstracts.

AB = Abstract

AU = Author

DE = Term from the thesaurus

MM = Major Concept

TI = Title

TX = All Text. Performs a keyword search of all the database's searchable fields

ZC = Methodology Index

* = Truncation

“ ” = Citation Marks; searches for an exact phrase

Cochrane Library via Wiley 23 January 2019 (CDSR)

Title: Transition of care from pediatric to adult services for young adults with type 1 diabetes

Search terms	Items found
Population: Diabetes mellitus hos barn, ungdomar och unga vuxna	
1. [mh "Diabetes Mellitus"]	26026
2. [mh "Chronic Disease"]	12337
3. (diabet* or chronic NEXT illness* or chronic NEXT disease* or chronic NEXT condition*):ti	40049
4. 1-3 (OR)	
Intervention: Strukturerad överföring från barnsjukvård till vuxenvård	
5. [mh "Transition to Adult Care"]	15
6. [mh "Transitional Care"]	25
7. ((transit* or transfer*) NEAR/6 (care or healthcare or program* or clinic* or self-care or self-manag* or manag* or plan* or intervent* or service* or process* or age or adult* or adolescen*)):ti,ab,kw	4843
8. 5-7(OR)	4843
Combined sets	
9. 4 AND 8	197 CDSR/2

The search result, usually found at the end of the documentation, forms the list of abstracts.

:au = Author

MeSH = Term from the Medline controlled vocabulary, including terms found below this term in the MeSH hierarchy

this term only = Does not include terms found below this term in the MeSH hierarchy

:ti = title

:ab = abstract

:kw = keyword

* = Truncation

"" = Citation Marks; searches for an exact phrase

CDSR = Cochrane Database of Systematic Review

CRD Database via Wiley 23 January 2019 (DARE, NHSEED, HTA)

Title: Transition of care from pediatric to adult services for young adults with type 1 diabetes

Search terms	Items found
Intervention: Strukturerad överföring från barnsjukvård till vuxenvård	
1. MeSH DESCRIPTOR Transition to Adult Care EXPLODE ALL TREES	6
2. MeSH DESCRIPTOR Transitional Care EXPLODE ALL TREES	0
3. (transit* OR transfer*):TI AND (care or healthcare or program* or clinic* or self-care or self-manag* or manag* or plan* or intervent* or service* or process* or age or adult* or adolescen*):TI AND (diabet* OR "chronic illness*" OR "chronic disease*" OR "chronic condition*"):TI IN DARE, NHSEED, HTA	5
Combined sets	
4. 1-3 (OR)	9

The search result, usually found at the end of the documentation, forms the list of abstracts.

MeSH = Term from the Medline controlled vocabulary, including terms found below this term in the MeSH hierarchy

this term only = Does not include terms found below this term in the MeSH hierarchy

:ti = title

* = Truncation

"" = Citation Marks; searches for an exact phrase

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