Illness intrusiveness in parents of youth with type 1 diabetes: A longitudinal study

Running Head: Longitudinal study parental illness intrusiveness

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Abstract

Objective. Type 1 diabetes in youth has a wide-ranging impact on families. This study aimed at a better understanding of experiences and difficulties that parents may encounter in their lives. Parental illness intrusiveness (i.e., a parent's perception that the illness of one's child interferes with one's personal life) was prospectively examined in mothers and fathers.

Methods. Parental dyads (*n*=291) completed four annual questionnaires on parental illness intrusiveness, depressive symptoms, and treatment adherence of their child. Youth reported on their treatment adherence.

Results. First, cross-lagged models showed that mothers' illness intrusiveness predicted relative increases in both mothers' and fathers' illness intrusiveness over time. Similar effects were found for fathers. Second, paired-samples *t*-tests revealed higher illness intrusiveness in mothers at baseline. Latent growth curve modeling showed that mothers' illness intrusiveness generally decreased over time, while fathers' illness intrusiveness remained constant. Third, from a person-centered approach, multivariate latent class growth analysis identified three classes of parental couples: one with low and decreasing illness intrusiveness (54%), one with slightly elevated illness intrusiveness that remained stable over time (37%), and one with high illness intrusiveness that decreased in mothers but remained stable in fathers (9%). More parental depressive symptoms were reported in this latter class, while treatment adherence did not differ among the classes.

Conclusions. Most parents in this sample reported rather low illness intrusiveness over time, yet some experienced a major impact of the illness. Examining parental illness intrusiveness may provide a better understanding of the specific challenges parents are confronted with.

Key words: Illness intrusiveness, mothers, fathers, adolescence, emerging adulthood

Type 1 diabetes in youth comes with an intensive daily treatment regimen.[1] The required illness-specific daily routines take a toll on patients' personal lives. However, their family members, and parents in particular, can be affected by the illness as well.[2] Throughout adolescence, treatment responsibilities are gradually transferred from parents to youth.[3] Parents and youth become partners in diabetes management, with youth increasingly assuming more responsibility and parents monitoring and providing support when needed.[1,4] At the same time, however, youth often show poor diabetes outcomes,[5] which may be particularly stressful for parents because they have to find a balance between supporting their child and allowing for more independence in its diabetes treatment. Hence, parents remain closely involved and can feel significantly burdened by the illness, even when their child transitions to adulthood.[1,4,6]

Studying parental illness intrusiveness may contribute to a better understanding of the challenges that parents of youth with type 1 diabetes encounter in life. Illness intrusiveness refers to the perceived impact of an illness on different domains of one's personal life, such as personal development, leisure activities, and financial status.[7] It has been widely investigated in patients themselves,[8] yet more recent work has also established its relevance in parents of children with chronic illnesses.[9] Up till now, parental illness intrusiveness has been examined in parents of children with juvenile rheumatic diseases,[10,11] (aged 9-19 and 7-18), sickle cell disease,[12] (aged 8-18) and, more recently, type 1 diabetes[13] (aged 14-25; using baseline data from the present sample). Parental illness intrusiveness partially overlaps with pediatric parenting stress,[14] caregiver strain,[15] and parental diabetes-specific distress.[6] While all of these constructs assess parental experiences related to raising a child with a chronic illness, parental illness intrusiveness is unique in its explicit focus on different domains of parents' personal lives. First, pediatric parenting stress refers to stress experienced by parents of a child with an illness in four possible domains: communication, emotional functioning, medical care, and role functioning.[14] Whereas the latter domain has some resemblance to parental illness

intrusiveness, previous studies have mostly used a combined total score of pediatric parenting stress without differentiating between these domains. In addition, parental illness intrusiveness assesses a wider array of personal life domains that are not covered by pediatric parenting stress (e.g., self-expression). Second, caregiver strain refers to difficulties, responsibilities, demands, and negative psychic consequences caregivers might be confronted with when caring for a chronically ill relative.[15] As items tapping into mood states (e.g., feeling sad or unhappy) are also included in its questionnaire, this may confound a clear distinction between parental illness-related experiences and their psychological well-being. Third, parental diabetes-specific distress captures parents' experiences directly related to the child's illness: parents' own distress, parents' distress about the diabetes management, parents' distress about their relationship with their child, and parents' distress about the health care team.[6] Compared to these constructs, the added value of parental illness intrusiveness lies in its assessment of a more diverse array of parents' personal life domains. In former studies, parental illness intrusiveness has been positively related to parental depressive symptoms.[10,11] Moreover, it could also relate to poorer diabetes outcomes in the child over time, similar to what has been found for caregiver strain.[2,16] Unfortunately, all former studies on parental illness intrusiveness have used cross-sectional designs. In addition, except for the type 1 diabetes sample,[13] no distinction was made between maternal and paternal illness intrusiveness.

In general, fathers have been largely underrepresented in pediatric psychology.[17] While mothers and fathers take on different roles in the diabetes management (with mothers often being more closely involved[18]), it is important not to overlook fathers. For instance, Wysocki et al.[19] observed that higher paternal involvement related to better treatment adherence. Regarding parental functioning, most studies that included both parents of children with type 1 diabetes used a comparative approach to identify differences between maternal and paternal functioning. Some studies reported no significant differences between mothers and fathers,[20]

whereas other studies found less psychological distress in fathers than in mothers.[21] Far less attention has been devoted to interdependencies and the (co-)development of maternal and paternal functioning. Mothers and fathers share the stressor of caring for their child with diabetes, but they also share a more general background, such as social support systems and socio-economic status. Consequently, their reactions are not independent from each other but they may rather function as an interdependent emotional system, similar to what has been found in parents of children treated for pediatric cancer.[22] This reasoning aligns with the family systems perspective,[23] which describes that change in one family member's functioning affects the functioning of other family members. Hence, examining the longitudinal interplay and development of maternal and paternal illness intrusiveness over time would contribute significantly to the existing knowledge of parental illness experiences.

The present study

The present study examined illness intrusiveness in mothers and fathers of youth with type 1 diabetes over a three-year period. Four main objectives were defined. Objective 1 addressed interdependencies between maternal and paternal illness intrusiveness over time. This dyadic approach is described in the actor-partner interdependence modeling framework (APIM)[24] that mainly focuses on interdependencies between two persons. It provides information on the impact that both parents would have on each other (partner effects). Higher illness intrusiveness in one parent was expected to be prospectively associated with higher illness intrusiveness in the other, aligning with theories stating that parental couples may react similarly to stressors.[22] APIM also estimates the stability of a person's illness intrusiveness over time (actor effects). Based on results on posttraumatic stress symptoms in families confronted with childhood cancer, mothers' and fathers' illness intrusiveness were expected to show rather high stability rates.[22]

For objective 2, general trends in maternal and paternal illness intrusiveness were estimated. Because mothers generally take a more central role in the diabetes management of their child,[18] mothers were expected to experience more impact in their personal lives (i.e., higher illness intrusiveness). Further, as youth gradually assume more responsibility in their diabetes management,[3] a decline in both maternal and paternal illness intrusiveness over time was anticipated.

For objective 3, a person-centered approach was used to group parental couples based on their development of parental illness intrusiveness over time. Research on developmental trajectories in parental functioning and illness experiences is scarce. Former work has emphasized considerable variation in caregiver adaptation to chronic illnesses with regard to well-being, mental health, and engagement in social roles.[25] As such, the identification of at least three classes was anticipated. First, one class would include parents reporting rather low and/or decreasing parental illness intrusiveness, as most parents seem to adapt relatively well and become accustomed to the illness over time.[18,25] A second class would represent parents with relatively high and/or increasing parental illness intrusiveness. Similar to findings illustrating that a subset of parental couples continue to report psychological distress,[2] we also expected such a class reporting high parental illness intrusiveness. Identifying these parents is clinically relevant as they may need more intensive psychological support compared to other parents who encounter fewer difficulties in their everyday life. Finally, based on research on family burden, one or two other classes could emerge with parents reporting somewhat elevated levels of illness intrusiveness, being situated between the classes with either relatively low or relatively high parental illness intrusiveness.[26]

Finally, for objective 4, the trajectory classes were compared on maternal and paternal depressive symptoms, and youth treatment adherence. The class with the highest parental illness intrusiveness was expected to report more depressive symptoms.[10,11] Poorer treatment

adherence was also expected in this latter class, being in line with comparable work showing associations between caregiver strain and poorer diabetes outcomes.[16]

Methods

Participants and Procedure

Data are part of a longitudinal study in youth with type 1 diabetes and their mothers and fathers. The study consisted of four measurement waves that spanned three years. At baseline (T1), participants were selected via the Belgian Diabetes Registry using the following criteria: (1) diagnosed with type 1 diabetes; (2) between 14 and 25 years old; (3) Dutch-speaking. The study was approved by the Medical Ethics Committee and Social and Societal Ethics Committee of KU Leuven. A detailed description of the study procedure can be found in Oris et al.[27] and Prikken et al.[13] At T1, 575 youth with type 1 diabetes (41%), 463 mothers (33%), and 384 fathers (27%) participated. At T2, youth that participated at T1 and their parents were invited. At T3 and T4, participants who had at least participated once were again invited. For the present study, parental dyads were selected (biological mother and biological father, or biological parent and stepparent) of which both parents participated at T1, were living together, and indicated that their child was still living in the parental home. This resulted in 291 dyads at T1, 239 mothers and 236 fathers at T2, 205 mothers and 196 fathers at T3, and 173 mothers and 167 fathers at T4.

To assess the potential selectivity of the study sample, several comparisons were made. First, the selected sample did not differ significantly from the full sample on parental illness intrusiveness at T1 [Mothers: $F(1,453)=1.50$, $p=.219$; Fathers: $F(1,376)=.003$, $p=.959$]. Second, in families with a participating mother and father, parental illness intrusiveness at T1 did not differ between the included dyads and the 24 dyads who were excluded because the child was not living with them [MANOVA; Wilks' Lambda=.993, $F(2,346)=1.14$, $p=.322$]. Similarly, no differences were found with the 39 dyads that were excluded because participating mothers and

fathers were not living together [MANOVA; Wilks' Lambda=.993, $F(2,323)=1.08$, $p=.341$]. As such, none of these analyses revealed any significant differences in parental illness intrusiveness between included and excluded parents. In addition, drop-out was not related to parental illness intrusiveness, as scores at a certain time point did not differ significantly between those who dropped-out at a later time point versus those who did not.

At baseline, mothers' mean age was 47.56 (*SD*=4.68) and 82.76% was employed. Fathers' mean age was 49.68 (*SD*=5.32) and 92.36% was employed at baseline. Regarding youth characteristics, 47.77% was male, with a mean age of 18.27 (*SD*=3.00) and a mean illness duration of 7.17 years (*SD*=4.63). The majority used insulin injections to administer insulin (79.31%), while a minority used a pump (20.69%).

Measures

Parental Illness Intrusiveness

Mothers and fathers completed the Illness Intrusiveness Scale – Parent Version,[9] based on the validated Illness Intrusiveness Ratings Scale.[28] They rated the experienced impact of their child's diabetes on, for example, leisure activities, relationship with spouse, and financial status on a 1 (not very much) to 7 (very much) Likert-scale. All 13 items were translated to Dutch using the back-translation procedure.[29] Sum scores were calculated at T1, T2, T3, and T4; higher scores indicated more parental illness intrusiveness. Cronbach's alphas varied between .91 and .93 for mothers and fathers at Time 1 to Time 4.

Parental Depressive Symptoms

The Center for Epidemiologic Studies Depression Scale (CES-D) was used for measuring parental depressive symptoms in the week before completing the questionnaire.[30,31] The CES-D consists of 20 items answered on a Likert-scale from 0 (rarely or none of the time – less than 1 day) to 3 (most or all of the time – 3 to 7 days). Maternal and paternal sum scores were

calculated at T1 and T4 with higher scores indicating more depressive symptoms. Cronbach's alphas varied between .89 and .94.

Treatment Adherence

The Self-Care Inventory (SCI)[32] assessed how strictly treatment guidelines were followed during the past month. Youth reported on their own adherence, parents reported on their child's adherence. One of the 14 items was removed (i.e., wearing a medic alert ID), because this is not always part of treatment in Belgium. Responses varied between 1 (never do it) and 5 (always do this as recommended without fail), or "not applicable". The SCI was back-translated to Dutch.[29] Mean scores were calculated for youth, maternal, and paternal reports at T1 and T4; higher scores indicated better treatment adherence. Cronbach's alphas varied from .68 to .80.

Statistical Analyses

The study was registered at Open Science framework, providing a more detailed analysis plan (www.osf.io/ne8yz). Mplus version 7.4 and IBM SPSS Statistics Version 25 were used. Little's missing-completely-at-random test[33] with all variables included was significant [$\chi^2(831)=900.35$, $p=.047$]. Data were assumed to be missing at random, and, hence, expectation maximization (EM)[a] was used for analyses in SPSS,[34] while the full information maximum likelihood procedure was used in Mplus.[35] Robust maximum likelihood accounted for data non-normality in Mplus.

For objective 1, APIM was applied using cross-lagged modeling[24] to examine the longitudinal interplay between maternal and paternal illness intrusiveness. According to APIM, actor effects (i.e., auto-regressive or stability paths) describe how much mothers'/fathers' illness intrusiveness is predicted by mothers'/fathers' own intrusiveness, respectively, at an earlier time point. Partner effects (i.e., cross-lagged paths) describe to what extent mothers' illness intrusiveness is predicted by fathers' illness intrusiveness at an earlier time point, and

[a] EM would initially be used for objective 4, but we used it for all analyses in SPSS to increase consistency, that is, also for correlational analyses (objective 1) and the paired-samples *t*-test (objective 2).

vice versa. Prior to testing cross-lagged models, correlations were calculated for maternal and paternal illness intrusiveness at each time point. Regarding control variables, correlations among illness duration, child's age, and parental illness intrusiveness at T1 were calculated. A MANOVA tested whether parental illness intrusiveness at T1 differed by type of insulin administration. As suggested by a Reviewer, the effect of child's gender on parental illness intrusiveness was also investigated using MANOVA. If significant associations with these control variables occurred, they were included in the cross-lagged models as well. Three models were tested and compared on their model fit. Model 1 was the unconstrained model, in which actor and partner effects could vary over time and could also differ between mothers and fathers. If control variables were included, all parental illness intrusiveness reports were initially regressed on these control variables. Thereafter, non-significant paths were trimmed to result in the final and more parsimonious version of Model 1. In Model 2, time-invariance was examined, meaning that all paths were fixed over time. Actor and partner effects could still differ between mothers and fathers. Model 3 assumed equal actor and partner effects for mothers and fathers. This implied that actor effects for mothers were set equal to actor effects for fathers. Partner effects for mothers on fathers were set equal to partner effects for fathers on mothers. Importantly, if Model 2 (assuming time-invariance) showed a good fit to the data, Model 3 would test whether fixed actor effects and fixed partner effects would hold as well, given that all effects were fixed over time. The three models were compared on the following fit indices[36]: The Satorra-Bentler χ^2 should be as small as possible; the Root Mean Square Error of Approximation (RMSEA) should be <.08; and the Comparative Fit Index (CFI) should be >.90. Satorra-Bentler scaled $\Delta\chi^2$ compared the fit of nested models.

Objective 2 investigated average levels and change over time in maternal and paternal illness intrusiveness. A paired-samples *t*-test compared maternal and paternal illness intrusiveness at T1. Latent growth curve modeling (LGCM) estimated mean intercepts and

slopes to describe average change trajectories of parental illness intrusiveness over time. Following Duncan et al.[37], two steps were taken. First, univariate LGCM was applied separately for maternal and paternal illness intrusiveness to check model fit and to test whether quadratic slopes should be included in the multivariate models in addition to intercepts and linear slopes[b]. Next, multivariate LGCM simultaneously estimated maternal and paternal illness intrusiveness trajectories, which provided correlations between parameters for mothers and fathers as well.

For objective 3, multivariate latent class growth analysis (LCGA), a person-centered approach, identified trajectory classes of illness intrusiveness in mothers and fathers.[38,39] For each class, intercepts, linear slopes, and possibly quadratic slopes were estimated[c]. Models with 1 to 5 classes were compared on the following criteria[38,40]: (1) a lower Bayesian information criterion (BIC) indicates a better fit. BIC differences larger than 10 provide evidence in favor of the model with the smallest BIC[41]; (2) the entropy is a standardized indicator of classification accuracy that varies from 0 to 1 and should be near 1; (3) the Lo-Mendell-Rubin Likelihood Ratio Test (LMR-LRT) and Bootstrapped Likelihood Ratio Test (BLRT) provide a *p*-value indicating whether the fit improves significantly by including an extra class; (4) theoretical justification, parsimony, interpretability, and the number of cases within classes were taken into account as well.

For objective 4, the latent classes of Objective 3 were compared on child's age, illness duration (ANOVAs), and type of insulin administration (cross-tabulation). Following a Reviewer's suggestion, the classes were also compared on child's gender (cross-tabulation). Next, MANOVAs compared the classes on maternal and paternal depressive symptoms at T1 and T4, and on treatment adherence as reported by youth, mothers, and fathers at T1 and T4.

[b] When means or variances around the quadratic slope did not significantly differ from zero or in case of convergence issues, the quadratic term was omitted here and in subsequent analyses.
[c] The inclusion of quadratic slopes depended on the results of research objective 2 and on convergence issues.

Wilks' Lambda was used to interpret multivariate effects. If significant, follow-up univariate ANOVAs and post-hoc comparisons using Tukey HSD procedure were interpreted.

Results

Objective 1: Interdependencies Between Maternal and Paternal Illness Intrusiveness

All correlations between maternal and paternal illness intrusiveness at T1, T2, T3, and T4 were significant ($p<.001$) and varied between .39 and .60. Illness duration correlated positively with maternal illness intrusiveness at T1 ($r=.16$, $p=.006$), and was included as a control variable in the cross-lagged analyses. Child's age did not correlate significantly with parental illness intrusiveness at T1 and the multivariate effects were non-significant for type of insulin administration [Wilks' Lambda=.99, $F(2,287)=1.91$, $p=.149$] and gender [Wilks' Lambda=1.00, $F(2,288)=0.41$, $p=.661$].

Model 1 initially showed poor model fit [$\chi^2(12)=81.45$; $p<.001$; RMSEA=.14; CFI=.84]. Except for one path from illness duration to maternal illness intrusiveness at T1 ($\beta=.16$, $p=.013$), all paths from illness duration were non-significant and were trimmed to increase parsimony. This trimmed model again showed poor model fit, which is why stability paths from T1 to T3 and from T2 to T4 were added. This resulted in the final version of Model 1 with good fit to the data [$\chi^2(15)=31.24$; $p=.008$; RMSEA=.06; CFI=.96]. Starting from this final Model 1, Model 2 tested whether time-invariance could be assumed. Good model fit was obtained [$\chi^2(25)=48.88$; $p=.003$; RMSEA=.06; CFI=.95], which was not significantly worse than Model 1 [$\Delta\chi^2(10)=18.15$; $p=.053$]. Hence, in Model 3, time-invariance was again assumed, and in this Model it was tested whether equal actor effects and equal partner effects would hold as well. Model 3 also fitted the data well [$\chi^2(28)=51.20$; $p=.005$; RMSEA=.05; CFI=.95] and there was no significant decrease in model fit compared to Model 2 [$\Delta\chi^2(3)=2.53$; $p=.470$]. Hence, Model 3 was preferred and in Figure 1, all standardized actor effects (i.e., cross-lagged paths), partner effects (i.e., stability paths), and within-time associations are shown. Positive actor effects

indicated that mothers' intrusiveness predicted relative increases over time in mothers' intrusiveness. For fathers, the same effects occurred. Positive partner effects indicated that mothers' illness intrusiveness predicted relative increases in fathers' illness intrusiveness at a later time point, and vice versa.

Objective 2: Average Levels and Development of Parental Illness Intrusiveness

A paired-samples *t*-test indicated significant differences between mothers' and fathers' illness intrusiveness at baseline [$t(290)=4.82$, $p<.001$]. Mothers ($M=31.26$, $SD=15.51$) reported higher illness intrusiveness than fathers ($M=27.02$, $SD=12.95$). Univariate LGCM showed that mean quadratic slopes and their variances were non-significant and they were hence left out in the multivariate models. The multivariate LGCM included intercepts, linear slopes, and all within-time correlations between maternal and paternal illness intrusiveness[d]. Good model fit was attained (See Table 1). In general, maternal illness intrusiveness decreased over time, while paternal intrusiveness remained stable. A positive correlation was found between maternal and paternal intercepts, while the correlation between maternal and paternal slopes was non-significant.

Objective 3: Latent Trajectory Classes in Parental Illness Intrusiveness

LCGA was used to identify different trajectory classes in the development of maternal and paternal illness intrusiveness. To decide on the number of latent classes, models with 1 to 5 classes were compared (See Table 2). The five-class solution was not chosen because one class represented only 3% of the sample. When comparing the four-class solution to the three-class solution, fit indices were inconsistent. For reasons of parsimony, the three-class solution was chosen. All fit indices preferred this three-class solution over the two-class solution.

As shown in Table 3, the first class reported rather low maternal and paternal illness intrusiveness as compared to the sample means of mothers and fathers, respectively, and was

[d] Within-time correlations were added after a warning occurred when running the initial multivariate model.

accordingly labeled as the low parental illness intrusiveness class. This was the largest class (54%), including parents who experienced relatively little impact of the illness on their own personal lives, which further declined over time in both mothers and fathers. The second class, labeled as the moderate parental illness intrusiveness class, included 37% of the parental couples. Parents in this class experienced slightly elevated levels of illness intrusiveness which remained stable over time in both mothers and fathers. The last class, labeled as the high parental illness intrusiveness class, included 9% of the parental couples and represented mothers and fathers with relatively high levels of illness intrusiveness as compared to the sample means of mothers and fathers, respectively. A decreasing trend was found in mothers, but not in fathers.

Objective 4: Parental Depressive Symptoms and Treatment Adherence among Classes

Prior to running MANOVAs, the role of potential control variables was explored at T1. Only for child's age, significant differences were found [$F(2,288)=3.24$, $p=.041$][e], with mean ages of 18.56 ($SD=2.96$), 17.72 ($SD=3.02$), and 18.92 ($SD=2.89$) for the low, the moderate, and the high parental illness intrusiveness class, respectively. Post-hoc testing, however, indicated that none of the specific differences between two classes were significant. No significant effects were found for illness duration [$F(2,286)=2.07$, $p=.128$], type of insulin administration [$\chi^2(2)=2.17$, $p=.339$], or gender [$\chi^2(2)=2.80$, $p=.246$].

For parental depressive symptoms at T1 and T4, overall multivariate effects were significant [Wilks' Lambda=.80, $F(8,570)=8.40$, $p<.001$]. Results of the univariate analyses and post-hoc tests are shown in Table 4. The high parental illness intrusiveness class reported more depressive symptoms than the low class, except for paternal depressive symptoms at T4. This high parental illness intrusiveness class also reported more depressive symptoms

[e] The MANOVAs testing the role of class membership were performed twice, with and once without age included as covariate. Similar results were found, and, hence, only the results from the MANOVAs without age were displayed together with the post-hoc tests.

compared to the moderate class, except for paternal depressive symptoms at T1 and T4. In addition, when comparing the moderate parental intrusiveness class to the low class, the moderate class reported significantly more depressive symptoms as well, except for paternal depressive symptoms at T4. For treatment adherence at T1 and T4, the multivariate effect was non-significant [Wilks' Lambda=.95, $F(12,566)=1.23$, $p=.258$]. Hence, treatment adherence did not differ significantly among the classes.

Discussion

This study was the first to prospectively chart parental illness intrusiveness in mothers and fathers of youth with type 1 diabetes. Many parents of adolescents and emerging adults experience illness intrusiveness to some extent, despite the general assumption that their involvement and responsibility in the diabetes management decline over time.[1,3] It may be particularly challenging for these parents to deal with their child's age-specific developmental tasks and changing parental roles, while also monitoring their child's diabetes treatment.[5] They have to let their child become more independent, yet at the same time they should also avoid deteriorating diabetes outcomes.[42] This could increase their stress levels and experienced parental illness intrusiveness. As mothers' and fathers' illness experiences may not be independent from each other, simultaneously addressing mothers and fathers should be encouraged.[43]

Interdependencies Between Parents over Time

The cross-lagged models provided evidence for both actor and partner effects, implying that maternal illness intrusiveness not only predicted relative increases in maternal intrusiveness at a later time point, but also in paternal intrusiveness. For fathers, the same results were found. The positive partner effects are of particular relevance and are in line with expectations: illness intrusiveness in one parent may indeed predict relative changes in the other over time.[23] This process may result from parents' shared views on the illness and their shared life

circumstances.[22] For clinical care, these findings encourage clinicians to assess illness intrusiveness in both parents to enable a timely identification of parents with elevated illness intrusiveness in order to avoid a vicious circle.

Development over time

In general, mothers experienced more impact of the illness than fathers. These higher rates of maternal illness intrusiveness were expected and could be explained by mothers' more central role in the diabetes management,[18] which may, in turn, translate into feeling more impact of the illness in their personal lives. Furthermore, illness intrusiveness in mothers decreased over time, while it remained constant in fathers. The increasing independence of youth may provide some relief for caregivers as they gradually change their involvement into monitoring and providing support, depending on the needs of their child.[1,4] For fathers, who are generally less closely involved in the diabetes management, this responsibility transfer may have been less prominent in their personal lives, which could explain why their illness intrusiveness did not decrease over time.

Apart from these differences between mothers and fathers, the results also provided evidence for a certain degree of similarity between mothers and fathers. Latent Class Growth Analysis identified three trajectory classes. Although mothers consistently experienced somewhat higher illness intrusiveness than fathers, the obtained classes included parental couples with rather low, moderate, and rather high illness intrusiveness in both mothers and fathers. First, the largest class consisted of parental couples of which both mothers and fathers reported relatively low levels of illness intrusiveness that further decreased over time. Next, there was a class with somewhat increased levels of parental illness intrusiveness that remained stable over time. Lastly, the smallest class consisted of 9% of the couples and represented parents with the highest illness intrusiveness that decreased over time in mothers but not in fathers. This latter class reflects a clinically important group of parental couples who may

experience a considerable impact of the illness on their own functioning. Moreover, these parents also experienced more depressive symptoms than parents in the other classes. In a recent study of Noser et al.[44] on the interplay between parental depressive symptoms and diabetes distress, it was found that parental depressive symptoms may exacerbate parental diabetes distress in the first year after diagnosis. Although directionality of effects was not addressed in the current study, the present findings also suggest a certain interplay between depressive symptoms and illness intrusiveness in parents that may last for multiple years after diagnosis. In general, the three identified classes align with the categories described in the 3-tier model of Kazak[45], also suggesting that only a relatively small subset of families would need more intensive psychosocial support in addition to standard services. As such, the potential value of parental illness intrusiveness to screen families at-risk should be tested in future studies.

Screening parents for depressive symptoms and illness intrusiveness shortly after diagnosis and in the long term is considered important because of potential associations with child depressive symptoms and poorer diabetes outcomes as well.[13,46] However, contrary to our expectations, treatment adherence did not differ among the classes in the current study. Previous research has established that parental distress and child outcomes may be rather indirectly related to one another, with parenting dimensions as intervening mechanism.[46] Hence, we would encourage the testing of reciprocal relationships between parental illness intrusiveness, parenting dimensions, and youth outcomes over time.

In general, however, the present results convey an optimistic message. In accordance with former findings that most parents are able to adapt well over time,[25] more than half of the parents in the present sample reported rather low levels of illness intrusiveness over time. They seemed to be able to maintain their functioning in a wide array of life domains without feeling overly limited in their daily-life functioning. One possible explanation may be that parents can experience positive effects of the illness as well, instead of merely experiencing negative

consequences.[42] These positive aspects of parental illness experiences are gradually gaining more attention. For example, Hungerbuehler et al.[47] found that most parents with children with type 1 diabetes or pediatric cancer in their study reported moderate levels of posttraumatic growth. Research on related constructs such as meaning in life and benefit finding have shown promising results as well.[48,49] In sum, it seems important to combine the assessment of parental illness intrusiveness with more positive indicators as this could shed more light on the interplay between risk factors and protective factors for parental illness adaptation and functioning.

Limitations and Suggestions for Future Research

Some limitations should be taken into account. First, the study used self-report data. Although self-report is well-suited to measure internal subjective experiences, it could induce shared method variance. Second, parental illness intrusiveness focuses on negative sequelae of the illness. Future research should integrate negative and positive illness experiences to provide a more nuanced view on risk and protective factors among parents caring for a child with type 1 diabetes. Third, response rates were rather low, which could have led to sampling bias and a limited generalizability of the findings. Fourth, time since diagnosis varied considerably and the current study only focused on adolescents and emerging adults. Regarding time since diagnosis, based on former work on parental diabetes-specific distress, we could expect an initial increase in parental illness intrusiveness in the first months after diagnosis, followed by a gradual decrease and eventually a stabilization.[44] Regarding child's age, parental illness intrusiveness may be more pronounced in younger age groups, as parents are primarily responsible for managing the diabetes during early and middle childhood.[2] Future work should study parental illness intrusiveness as a function of both illness duration and typical developmental challenges. Fifth, time-intervals of one year are too long to capture short-term fluctuations in parental illness intrusiveness. Diary studies could provide more detailed information on this issue.

Notwithstanding these limitations, the study provided further evidence for the importance of including mothers and fathers in research on family adaptation to chronic illness throughout adolescence and emerging adulthood. Using the construct of parental illness intrusiveness in research and clinical work may be an important step toward a better understanding of the specific challenges parents are confronted with.

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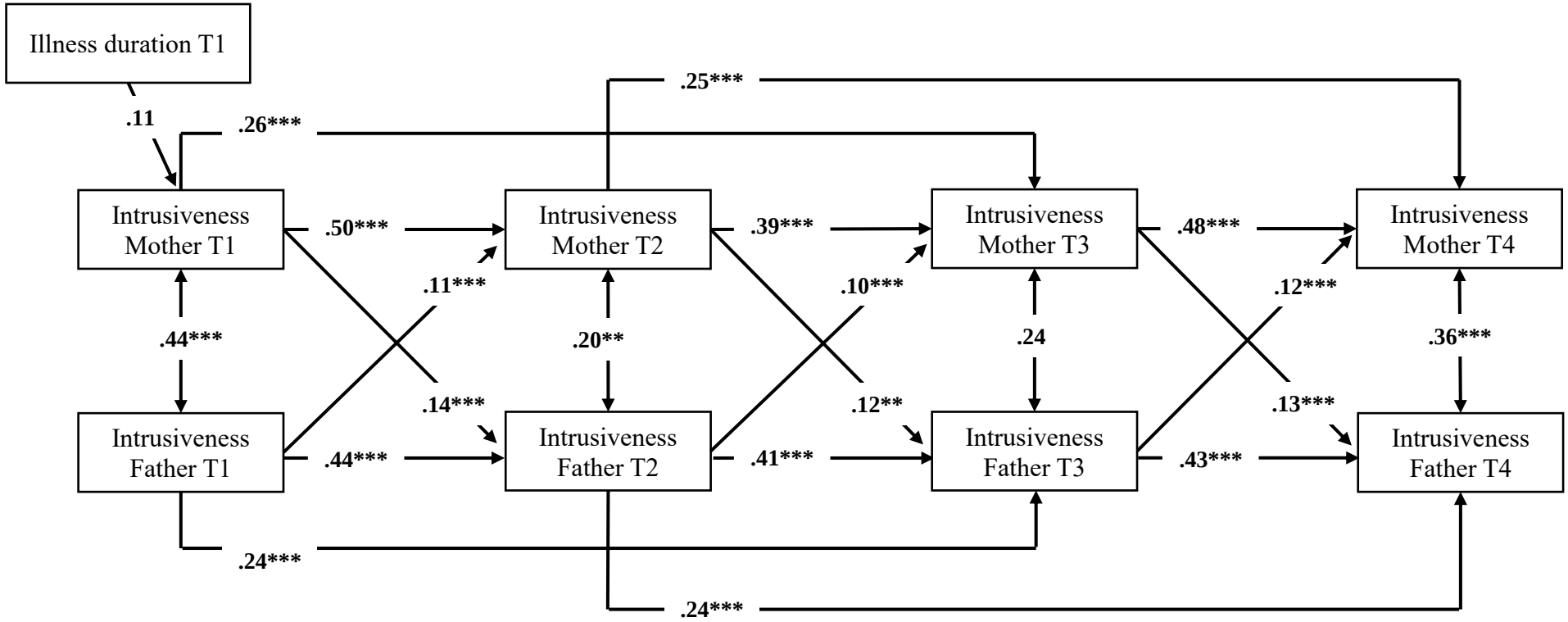

Figure 1. Cross-lagged model linking maternal and paternal illness intrusiveness over time. All coefficients are standardized.

*p<.05; **p<.01; ***p<.001.

Table 1

Multivariate Latent Growth Curve Modeling for Maternal and Paternal Illness Intrusiveness

				Intercept			Slope		
	χ^2(df)	RMSEA	CFI	*M*	S^2	*r(mother,father)*	*M*	S^2	*r(mother,father)*
Multivariate LGCM	23.76(18)	.03	.99			.53***			.20
Maternal Illness Intrusiveness				30.77***	151.50***		-1.01***	2.47	
Paternal Illness Intrusiveness				26.49***	94.85***		-0.32	1.95	

Note. *n*=291; Parental illness intrusiveness can vary from 13 to 91;
Correlations between maternal intercept and maternal slope were -.33 (*p*=.117) and between paternal intercept and paternal slope -.19 (*p*=.557).
LGCM = Latent Growth Curve Modeling; χ^2 = Chi Square statistic; RMSEA = Root Mean Square Error of Approximation; CFI = Comparative Fit Index; *M* = mean; S^2 = Variance; *r* = correlation;
*p<.05; **p<.01; ***p<.001.

Table 2

Multivariate Latent Class Growth Analyses on Maternal and Paternal Illness Intrusiveness

					Trajectory Group Prevalence (%)				
	BIC	Entropy	LMR-LRT	BLRT	1	2	3	4	5
1 Class	14567.84	/	/	/	100				
2 Classes	14152.98	.91	$p = .535$	$p < .001$	14	86			
3 Classes	**13969.18**	**.81**	$\mathbf{p = .034}$	$\mathbf{p < .001}$	**54**	**37**	**9**		
4 Classes	13888.55	.83	$p = .203$	$p < .001$	6	16	20	57	
5 Classes	13848.91	.84	$p = .448$	$p < .001$	23	3	53	5	15

Note. n=291; BIC = Bayesian Information Criterion; LMR-LRT = Lo-Mendell-Rubin Likelihood Ratio Test; BLRT = Bootstrapped Likelihood Ratio Test; The solution in bold was selected.

Table 3

Final Parameter Estimates of Latent Class Growth Analyses on Maternal and Paternal Illness Intrusiveness

	Parental illness Intrusiveness Trajectory Class		
	Class 1 (54%)	Class 2 (37%)	Class 3 (9%)
	Low Intrusiveness Class	Moderate Intrusiveness Class	High Intrusiveness Class
Maternal Illness Intrusiveness			
Mean intercept	23.08***	34.56***	66.07***
Mean slope	-1.35***	0.05	-4.70***
Paternal Illness Intrusiveness			
Mean intercept	21.10***	30.94***	42.64***
Mean slope	-0.70*	-0.17	0.93

Note. *p<.05; **p< .01; ***p<.001.

Table 4

Univariate Analysis of Variance and post-hoc comparisons based on Tukey HSD Tests for the Latent Trajectory Classes at T1 and T4

	Total	Parental illness Intrusiveness Trajectory Class			F-value (η^2)
		Low	Moderate	High	
Maternal Depressive Symptoms T1	9.86 (8.92)	7.40 (6.64)[a]	11.19 (9.45)[b]	19.48 (11.39)[c]	25.35*** (.15)
Maternal Depressive Symptoms T4	9.96 (8.26)	7.78 (6.54)[a]	11.75 (8.26)[b]	15.88 (12.57)[c]	15.95*** (.10)
Paternal Depressive Symptoms T1	7.29 (7.20)	5.73 (5.63)[a]	8.58 (7.65)[b]	11.52 (10.73)[b]	10.38*** (.07)
Paternal Depressive Symptoms T4	7.38 (6.74)	6.47 (6.26)	8.21 (6.73)	9.47 (8.78)	3.53* (.02)
Treatment Adherence Youth Report T1	3.81 (0.49)	3.80 (0.49)	3.85 (0.48)	3.74 (0.55)	0.60 (.00)
Treatment Adherence Youth Report T4	3.76 (0.39)	3.76 (0.40)	3.76 (0.39)	3.77 (0.38)	0.03 (.00)
Treatment Adherence Mother Report T1	3.91 (0.51)	3.95 (0.49)	3.87 (0.51)	3.77 (0.61)	1.72 (.01)
Treatment Adherence Mother Report T4	3.96 (0.44)	3.99 (0.44)	3.91 (0.43)	3.96 (0.47)	1.12 (.01)
Treatment Adherence Father Report T1	3.95 (0.51)	4.01 (0.53)	3.91 (0.50)	3.82 (0.36)	2.14 (.02)
Treatment Adherence Father Report T4	4.01 (0.43)	4.06 (0.43)	3.95 (0.44)	3.95 (0.41)	2.47 (.02)

Note. n=291. Standard deviations are given within parentheses. Different superscripts reflect significantly different means between two classes (p<.05). A mean without a superscript is not significantly different from other means.
*p<.05; **p<.01; ***p<.001.