# Clinical adolescent decision-making: Parental perspectives on confidentiality and consent in Belgium and The Netherlands

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## Clinical adolescent decision-making: Parental perspectives on confidentiality and consent in Belgium and The Netherlands

**Abstract:** This study investigated Belgian and Dutch parental opinions on confidentiality and consent regarding medical decisions about adolescents. Through an online survey, we presented six cases (three on confidentiality, and three on consent) to 1,382 Belgian and Dutch parents. We studied patterns in parental confidentiality and consent preferences across and between cases through binomial logistic regressions and latent class analysis. Participants often grant the right to consent for a treatment to the adolescent, but the majority diverges from the adolescent's preferences regarding confidentiality. More educated participants would rather not be informed about cases regarding a sexually transmitted disease or depression than lower educated participants. Further analysis shows that participants' preferences correspond to authoritative (47%), permissive (30%) and authoritarian (17%) parenting styles. Belgian and Dutch parents are willing to grant some degree of autonomy, but they want to be informed about specific health issues. Parental views on confidentiality and granting consent appear to mirror existing parenting styles.

Key words: Adolescents, Parenting style, Parenting, Medical decision-making, Minors

#### Introduction

Parents experience the full spectrum of their child's development from infancy to adulthood. They need to adapt their parenting to these stages. During this transition, one of the most challenging tasks is granting autonomy to their child as they mature (Peterson & Bush, 2015). This becomes even more challenging during adolescence, as youth often develop and seek greater independence from their parents (McElhaney et al., 2009; Peterson & Bush, 2015). This tension between adolescents' growing autonomy and parental involvement may lead to potential tensions between adolescents and their parents' preferences (McElhaney et al., 2009), and may also depend on the parenting style (Partridge, 2010; Power, 2013).

Scholars agree that there are two broad dimensions of parenting: parental support and parental control. Based on combinations of these two dimensions, four parenting styles have been developed: authoritative (high control and high support); authoritarian (high control and low support); permissive (low control and high support); and neglectful (low control and low support) (Kuppens & Ceulemans, 2019; Maccoby & Martin, 1983; Power, 2013; Van Leeuwen et al., 2004).

In medical contexts, tensions between adolescents and parents regarding autonomy may be particularly salient (Carlisle et al., 2006; Duncan et al., 2011; Sasse et al., 2013; Song et al., 2019). Decisions regarding treatment in pediatric settings are often believed to occur along a continuum: at one end, the patient and/or parents are fully responsible (autonomous decision-making), while at the other end, the physician has full responsibility (paternalistic decision-making) (Lipstein et al., 2012). Most decision-making occurs between these two extremes, with shared decision-making often viewed as the ideal scenario. Here, the physician, patient, and parents collaborate to select a treatment option in line with everyone's values and preferences (Charles et al., 1999; Park & Cho, 2018). However, when patients (i.e., children) and parents disagree about the preferred treatment option, the model of shared decision-making becomes difficult to sustain. This study focuses on two constructs that increasingly cause strain on the relationship between patient, parents, and physician: confidentiality and consent (Jackson et al., 2014; Sasse et al., 2013; Song et al., 2019). With regards to confidentiality, studies have shown that parents and adolescents often disagree on the degree of confidentiality that should be maintained during medical consultations – regardless of legislation regarding this point (Ford et al., 2016). As long as the adolescent is a legal minor, parents often want to be informed about their treatment (Carlisle et al., 2006). Regarding consent, various medical situations occur in which adolescents want to consent to their own treatment without or against the approval of their parent(s) (Jackson et al., 2014). This can be cause for significant intrafamilial conflict, for example when parents are expected to pay for the treatment. When minors are considered medically competent by their physician or they reach a certain age, they are able make their own decisions about treatment without their parents' consent (Kuther, 2003; Larcher & Hutchinson, 2010). In the two countries under study, Belgium and The Netherlands, this legal context differs. In The Netherlands, minors from the age of 16 are considered mature to make medical treatment decisions without parental involvement (Dutch Civil Code, 1992a). In Belgium, a minor can exercise their rights autonomously if the physician decides that the adolescent is competent to have a reasonable judgement of their interests (i.e., maturity principle) (FOD Volksgezondheid, 2002).

Parental attitudes regarding confidentiality and consent are likely to have an impact on medical decision-making among adolescents: adolescents who believe their parents disapprove of or insist on knowing what is discussed with healthcare providers have higher odds of delaying or foregoing healthcare, which may have adverse short- or long-term health repercussions (Thrall et al., 2000). Despite this, parental attitudes regarding these confidentiality and consent in medical decision-making have received limited attention in the literature (De Coninck et al., 2021). While shared decision-making is considered to be the ideal model in pediatric decision-making, most studies focus on the role of the physician or adolescent (Lipstein et al., 2012). Limited – often qualitative – evidence regarding parental attitudes indicates that parents want to be informed about confidential interactions with a physician and often do not support full autonomy for adolescent medical decision-making (Carlisle et al., 2006; Duncan et al., 2011; Sasse et al., 2013; Song et al., 2019). Most studies on this topic have been conducted in the United States (Lipstein et al., 2012), with evidence from Europe and diverse medical contexts sorely lacking. In this study, we investigate parental perspectives on confidentiality and consent in clinical decision-making for adolescents in Belgium and The Netherlands through an online survey of 1,382 parents. We contribute to the literature on this topic by a) supplementing the existing qualitative insights with largescale quantitative data, and b) providing some of the first European perspectives on this topic.

#### Confidentiality and consent in adolescent medical decision-making

Discussions regarding autonomy frequently occur during medical consultations with adolescents (Carlisle et al., 2006; Duncan et al., 2011; Sasse et al., 2013; Song et al., 2019). During such discussions, the traditional dyad (physician-patient) has to be widened to a triad (physician-patient-parent(s)) in which all the members play a role in a process of shared decision-making (Lipstein et al., 2012). Such a widening is often viewed as the ideal scenario (Fiks & Jimenez, 2010). Here, physicians provide the medical expertise and the parents contribute in-depth knowledge about the child or adolescent (Ford et al., 2016; Jackson et al., 2014). In spite of the view that shared decision-making provides the most advantageous decision-making dynamic for all parties involved (Lipstein et al., 2012; Park & Cho, 2018), physicians regularly have to cope with conflict situations between parents and their adolescent children regarding medical treatments or information (Song et al., 2019). In addition to their involvement in decision-making, privacy and confidentiality is of great importance to adolescents (De Coninck et al., 2021). Research shows that many adolescents value confidentiality during consultations and would sometimes prefer to be alone with their physician (Carlisle et al., 2006; De Coninck et al., 2021). This is especially true for girls (Carlisle et al., 2006) and is consistent with research on adults which shows that men tend to have greater faith than women in the preservation of confidentiality by healthcare professionals (Shickle et al., 2002). However, some parents (strongly) oppose the idea that their child should be allowed to decide on an optimal medical treatment for themselves independently. When asked about their reasons for this stance, parents refer to the parental role they want to fulfil and the responsibilities associated with this role until their child is of legal age (Sasse et al., 2013; Song et al., 2019). Their main concern is that the child would be unaware of significant health issues (Duncan et al., 2011). However, some preliminary studies have indicated that these parental preferences depend on the type of medical issue under consideration (Stavleu et al., 2022).

Parents consider the benefits of confidentiality. For example, they are aware that more intimate health issues are more easily discussed during a private consultation with a trusted physician, without parents present (Duncan et al., 2011). Despite the complex familyand health-related situations that may arise from these tensions and the mismatch in terms of perceptions between parents and adolescents (De Coninck et al., 2021), relatively little research has been conducted on these perceptions and opinions. Family scholars and medical experts argue that adolescents' decisions – if they are considered competent by a physician – should always be respected even though these adolescents may be legally too young to provide consent (Berlan & Bravender, 2009; Ford et al., 2004). Studies show that adolescents can make rational decisions. However, in emotional situations, more irrational and intuitive decisions may be made (Diekema, 2020).

An ethical consideration is whether adolescents should be able to consent to their own treatment without or against the approval of their parent(s) (Jackson et al., 2014). There are several scenarios in which this may become difficult for health professionals to navigate (e.g., an adolescent wants to have surgery that parents do not want to pay for). Although efforts are being made to improve training in adolescent healthcare, studies have shown that a large portion of physicians continue to be uncomfortable when they are asked to provide care for sensitive health issues, like sexual or reproductive health, and/or when providing confidential care to adolescents (Wright et al., 2017). Studies in several countries have shown that less than half of patients are aware of their rights, and that these rights are not always respected (Devroey et al., 2013).

#### Understanding adolescent autonomy through parenting styles

The potential impact of parenting styles on the medical decision-making dynamic cannot be underestimated. Partridge (2010) argues that these parenting styles can aid adolescents become competent adult decision-makers. More specifically, "a considerable body of data concerning the general influence of permissive, neglectful, authoritative, and authoritarian parenting styles indicate that parents by setting limits to and providing direction for the decision making of adolescents in the end augment these decisional capacities" (Partridge, 2010, p. 522). Contrary to what may be assumed, setting certain limits to the adolescent's autonomy appears to enhance the adolescent's growing autonomy rather than undermine its development (Partridge, 2010). Specific attention has been paid to the authoritative parenting style. Various studies have shown that this parenting style is linked to increased autonomy, competence, and self-esteem (Baumrind, 1989), while it also cultivates the ability to resist harmful lifestyle choices (e.g., substance abuse) (Huver et al., 2007; Shakya et al., 2012). Yao et al. (2021) showed that authoritarian and permissive parents were inclined to breach confidentiality between adolescents and mental health professionals (e.g. ask the

mental health professional to inform them of the condition of their child).. Authoritative parents were considerably less likely to want to breach confidentiality than authoritarian or permissive parents. This recent study by Yao et al. (2021) represents the only one that linked parenting styles to preferences regarding confidentiality or consent. With these findings in mind, it seems plausible that parental preferences regarding confidentiality and consent may resemble or be linked to parenting styles: depending on the parenting style in question (authoritarian, permissive, authoritative), parental preferences towards confidentiality appear to differ.

#### This study

Different viewpoints of parents regarding confidentiality and consent complicate medical decisions regarding adolescents. National legislators have addressed the involvement of minors in medical decision-making in various ways. In European countries, the rights of an adolescent to make medical decisions (or ask the physician to keep information confidential) is based on three factors: (a) maturity assessment, (b) age (between 14 to 17 years of age, depending on the country) or (c) reaching the age of majority (18 years of age) (EU Agency for Fundamental Rights, 2021). The two countries under study (Belgium and The Netherlands) differ in this regard. In The Netherlands, all minors from the age of 16 are considered sufficiently mature to make medical treatment decisions without their parents' involvement (Dutch Civil Code, 1992a). In Belgium, a minor can exercise their patient rights autonomously if the physician decides that the adolescent is competent to have a reasonable judgement of their interests (i.e., maturity principle) (FOD Volksgezondheid, 2002). This approach leaves the decision with the physician, who has to independently assess the ability of the minor to decide the (legal) degree of parental involvement. Despite the different legal context between these two countries, the literature provides no indication on whether or how this would translate to regional differences in parental attitudes regarding confidentiality and consent. As such, it remains an open question if regional differences will be found based on our analyses.

As mentioned, there are a limited number of studies regarding parental opinions on medical decisions in children with the majority being qualitative or descriptive (Lipstein et al., 2012; Stavleu et al., 2022). At present, there are no data regarding the specific opinions of Belgian and Dutch parents on this issue. These neighboring countries provide an interesting frame of comparison, as they are a) culturally homogeneous (Vromans et al., 2013) but b) adopt different legal perspectives on the role of adolescents in medical decision-making, as highlighted above (Dutch Civil Code, 1992b; FOD Volksgezondheid, 2002). In this study, we evaluate parental perspectives regarding medical decision-making in adolescents. We studied this through an online survey and by applying a casuistic methodology (i.e., presenting several fictional scenarios). This methodology is an often-used strategy to resolve issues in (medical) ethics. Although the methodology has also received considerable criticism (Rubeis & Steger, 2017), casuistry is a valid method to investigate the logical consistency of ethical reasoning. It has the capacity to reveal "inconsistencies in ethical thinking and in making ethical debates clearer and fairer" (Spielthenner, 2016, p. 430). It is less suitable as a method of justifying ethical decisions, which is not the purpose of this article. In addition, we investigated the extent to which responses to the different cases correspond to different parenting styles. As shown by Yao et al. (2021), parenting styles are linked to parents' desire to breach confidentiality in specific settings. The information presented in this article may be of interest to physicians who are forced to navigate complex intrafamilial contexts and tensions between parents and their adolescent child during medial decision-making, but may also be useful for policy makers to identify ways in which current legislation on this topic insufficiently protects adolescents who wish to make medical decisions of their own accord.

#### Methods

#### Study design

We used a case-based online questionnaire (see Appendix A for a full overview of the cases) to examine parental opinions on medical decision-making in adolescents. We constructed six cases: three cases on confidentiality and three on consent. Each case deals with a specific topic in the medical treatment of a minor that could lead to discord. The KU Leuven Social and Societal Ethics Committee approved the study (case number G-2020-1670-R4).

Participants were recruited via a survey agency with large opt-in panels (over 150,000 individuals) in Belgium and The Netherlands. An e-mail was sent to potential respondents with the request to participate in this study – no subject matter was specified at this time. The survey took about 10 minutes to complete and was fielded for three weeks in October of 2020. Only participants who completed all questions in the survey were included in the final dataset. As such, there were no missing data. 1,000 Belgian and 1,000 Dutch respondents

were included, all ranging between 35-55 years of age to maximize their likelihood of having a teenage child. Apart from age, there were no other inclusion criteria. Following initial analyses, we found that 1,382 respondents (656 in Belgium, 726 in The Netherlands) had at least 1 child. All subsequent analyses were conducted on this subsample of parents. The gender distribution was 40% male – 60% female.

#### Measures

Firstly, participants completed a number of close-ended questions on demographic characteristics: gender (male/female), age, educational attainment (no education, primary education, secondary education, higher non-university education, university education), number of children and family composition (married, unmarried cohabitation, divorced, separated following unmarried cohabitation, single and never married, widowed). Educational attainment was recoded into a binary variable with 'no education', 'primary education', and 'secondary education' grouped under 'secondary education or lower', and 'non-university higher education' and 'university education' recoded to 'higher education'. Family composition was recoded into three categories: 'intact family unit' (married, unmarried cohabitation), 'non-intact family unit' (divorced, separated following unmarried or widowed'.

Secondly, we presented participants with six cases and asked them to respond as the parent of the (fictional) fifteen-year-old described in the cases. In the three cases on confidentiality, we used a sexually transmitted disease (STD), ultrasound examination and depression as topics. Maxillofacial/cosmetic surgery, migraine and ADHD were the topics for the three cases regarding consent. The authors constructed the cases, drawing on their real-life experiences in pediatric consultations. We aimed to include a variety of cases ranging from more to less severe, from physical to mental health problems, and from health issues that are considered easy to discuss (e.g., migraine) to issues that are considered to be more difficult (e.g., STD). We chose to do so because in their qualitative study on parental perceptions on confidentiality, Sasse et al. (2013) indicate that parents are more eager to be informed when the medical problem is more severe. The fictional adolescent in the cases was 15 years old. We chose this age because in The Netherlands, minors from the age of 16 are considered legally mature to independently make medical decisions (Dutch Civil Code, 1992a). In Belgium, the physician decides when an adolescent is competent to have a

reasonable judgment of their interests (FOD Volksgezondheid, 2002). By selecting a 15-yearold, we tried to ensure that all participants can imagine the situation with an adolescent who may not be considered mature enough to make an autonomous treatment decision – which would not be the case for Dutch participants if the adolescent was 16 years or older. The cases were piloted prior to the implementation of the study among colleagues and other contacts of the authors in the age range of 35 to 55 years old. Following this, some minor changes in terminology were implemented. An overview of the specific wording of the cases can be found in Appendix A.

#### Statistical analysis

Descriptive statistics were used to calculate and represent the demographic information. As the case-based questionnaires have two answer options, we conducted binomial logistic regressions (one per case) to identify which sociodemographic factors were significantly associated with the odds of confidentiality or consent preferences. To do so, we recoded Case 4 and Case 5 so that 0 = goes against the adolescent's request and 1 = goes along with the adolescent's request. For the other cases, 0 represented going against the adolescents request regarding confidentiality or consent and 1 corresponded to an adolescent-centered view that supports confidentiality or consent. Following the discussion in the literature review regarding the potential role of parenting styles and the link with adolescent autonomy (Yao et al., 2021), we also wanted to investigate if underlying patterns in the responses to the cases could be found that showed similarities to the existing parenting styles. We performed a latent class analysis to identify subgroups (classes) in the subsample based on commonalities in their responses to the confidentiality and consent cases. To provide further insight into the different ways in which these classes differ by sociodemographic factors, we included gender, region, and educational attainment as covariates to investigate the probability of class membership based on these characteristics. This allows us to analyze to what extent the probability of belonging to a certain class differs between men and women, Belgium and The Netherlands, and low or more educated participants. The descriptive and binomial logistic regressions were conducted in SPSS Version 26, the latent class analysis was conducted in SAS Version 9.4.

#### Results

The demographic characteristics of the participants are shown in Table 1: the mean age of respondents was 46 years, 60% of the subsample were female, and 54% had enjoyed a higher education. The results in Table 2 indicate that, in terms of confidentiality preferences in Belgium and The Netherlands, most parents wanted the physician to report the STD to them. Only 37% of the Belgian parents and 46% of Dutch parents did not want to be informed. The majority of Belgian (78%) and Dutch (68%) parents wanted to know the reason for the ultrasound. In Belgium and The Netherlands, respectively 26% and 38% of parents did not want the physician to inform them about the case of depression or suicidal ideation. These parents may leave confidentiality with the adolescent because they support and trust the physician and/or the adolescent (e.g., those with an authoritative parenting style), but it may also be due to a lack of interest in the adolescent in general (i.e., neglectful parenting).

Regarding cases on consent, the majority of the Belgian (65%) and Dutch (62%) participants wanted the fictional adolescent to take the medication for ADHD. Most parents (70% in Belgium and 68% in The Netherlands) would allow the minor to continue with the maxillofacial surgery. 83% of the Belgian parents and 74% of the Dutch parents agreed with the decision of the adolescent to take medication for the migraine.

In %	Belgium Netherlands		Total	
Gender				
Female	52.5	66.8	60.0	
Male	47.5	33.2	40.0	
Education				
Secondary education or lower	33.7	56.6	45.6	
Higher education	66.3	43.4	54.4	
Family situation				
Intact family	86.0	79.2	82.4	
Non-intact family	12.2	13.8	13.0	
Never married or widowed	1.9	7.0	4.5	
In mean score (SD)	Belgium	Netherlands	Total	
Age	46.02 (6.08)	46.72 (5.75)	46.38 (5.92)	

Table 1. Demographic overview of the subsample (n = 1,382)

In %	Belgium	Netherlands	Total
Case 1 (STD)	37.3	46.0	41.9
Case 2 (Ultrasound)	22.3	31.7	27.2
Case 3 (Depressed mood)	26.2	37.7	32.3
Case 4 (ADHD)	34.6	38.9	36.6
Case 5 (Maxillofacial surgery)	69.8	67.6	68.7
Case 6 (Migraine)	82.9	73.8	78.1

Table 2. Share of participants that follow adolescent's preference

#### Multivariate analysis

Table 3 displays the results of the binomial logistic regressions. For case 1 and 4 (regarding the STD and ADHD respectively), gender (of the participant) was significantly associated with the odds of confidentiality or consent preferences. Women had a lower likelihood than men to want to be informed about the STD (OR = 1.46, p < .01) and to stop the ADHD medication (OR = 1.83, p < .001). Age was significantly linked with all three cases on confidentiality preferences, but not with those on consent: older parents (aged 45 to 55 years old) had a higher likelihood of indicating that parents should not be informed about situations regarding the STD, ultrasound, or depression than parents aged 35 to 45 years old. Educational level was strongly related to confidentiality and consent preferences. Participants with a higher education had higher odds of leaving confidentiality decisions with the adolescent, i.e., not being informed about the medical situations regarding the STD, ultrasound, or depression (all confidentiality cases). They also presented with higher odds of supporting the adolescent in stopping the ADHD medication, but reported lower odds of supporting it in the maxillofacial surgery than lower educated parents.

As for regional differences, Belgian parents reported lower odds of leaving confidentiality decisions with the adolescent for all confidentiality cases than Dutch respondents, particularly for the case regarding depression (OR = 0.55, p < .001). However, they did report higher odds of supporting it in stopping the migraine medication than Dutch parents (OR = 1.85, p < .001).

	Case 1	Case 2	Case 3	Case 4	Case 5	Case 6
Gender (ref: male)						
Female	1.46**	1.00	1.25	1.83***	0.88	0.91
Age	1.35*	1.42**	1.33*	0.99	1.04	1.26
Education (ref: secondary or						
lower)						
Higher education	1.31*	1.36*	1.59***	1.35*	0.77*	0.79
Family situation (ref: intact						
family)						
Non-intact family	0.74	0.79	0.97	0.85	0.87	1.24
Never married or	1 10	1 10	0 99	0.88	1 15	1 16
widowed	1.10	1.10	0.55	0.00	1.15	1.10
Region (ref: Netherlands)						
Belgium	0.70**	0.58***	0.55***	0.86	1.18	1.85***
Constant	0.50***	0.33***	0.35***	0.37***	2.52***	2.76***
R <sup>2</sup>	.02	.02	.03	.03	.01	.02

Table 3. Binomial logistic regression analysis

Note: \*\*\* *p* < 0.001; \*\* *p* < 0.01; \* *p* < 0.05. Odds ratios presented.

#### Latent class analysis

Values of the Akaike Information Criterion (AIC), Consistent Akaike Information Criterion (CAIC), and Bayesian Information Criterion (BIC)were used to assess which model and number of classes provided the best fit with the data. The model with the lowest values for these indicators represented the most optimal fit (Nylund-Gibson & Choi, 2018). After running six models, ranging from 1 to 6 classes, the AIC (92.32), CAIC (260.57) and BIC (233.57) were found to be lowest in the model with four classes. In addition, the p-value for the -2 Log Likelihood test when adding a fifth class was not significant, which yielded additional support for a 4-class solution. With this, we used both information criteria and likelihood-based ratio testing – the two most common types of fit indices for LCA models – to determine the most optimal class solution given the present data (Nylund-Gibson & Choi, 2018).

Our findings showed that 20% of respondents were classified in class 1 (see Table 4). These respondents were the most restrictive of all parents: they presented with the lowest probability to allow both confidentiality and consent for adolescents. Class 2 represented the largest share of respondents (45%). They also presented with low probabilities of leaving confidentiality with adolescents, but held more positive views towards consent. Class 3 was made up of 28% of respondents and they held positive views towards adolescents'

confidentiality and consent, and – with the exception of the case on ADHD – presented with high probabilities of leaving decisions about confidentiality and consent with the adolescent. Class 4, which represented the smallest share of the sample (7%), held positive views towards adolescents' confidentiality but rather restrictive views when it came to consent. In a final step of the LCA we investigated to what extent gender, region, and educational attainment were predictors of class membership. Before adding the covariates, we tested for measurement invariance across groups (for an overview of this procedure, see Lanza et al., 2007) – in other words, whether the four-class model was the same across all groups of the covariates. For gender, measurement invariance testing indicated that the meaning of the latent classes differed across groups ( $G^2$  difference = 70.28; df difference = 24). For region and educational attainment, the model was stable across groups. -2 Log Likelihood testing indicated that region (p < .001) and educational attainment (p = .026) were significant predictors of class membership. With the restrictive Class 1 as the reference, results indicate that Belgians were nearly 50% more likely to be in Class 2 – holding more lenient views on consent, but not confidentiality. However, they were 32% less likely to be in the overall permissive Class 3 than in Class 1. With regards to education, the main difference was found between Class 1 and 2: highly educated participants were 36% less likely to be in the class that was supportive of adolescent consent but not confidentiality (Class 2) than they were to be unsupportive of both consent and confidentiality (Class 1).

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	Class 1	Class 2	Class 3	Class 4
Case 1 (STD)	.24	.18	.83	.84
Case 2 (Ultrasound)	.03	.02	.72	.80
Case 3 (Depressed mood)	.06	.07	.78	.89
Case 4 (ADHD)	.42	.26	.41	.72
Case 5 (Maxillofacial surgery)	.24	.90	.75	.34
Case 6 (Migraine)	.41	.95	.92	.23
Share of participants per class	20	45	28	7
Region (ref: Netherlands)				
Belgium	-	1.99	0.68	1.13
Education (ref: secondary or				
lower)				
Higher education	-	0.64	1.01	0.94
Note: Values presented are item re-	snonse prohahil	lities (0 - mini	mum prohabilit	w of preferring

able 4. Latent Class Analysis on parenta	al perspectives on	n confidentiality and	consent
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Note: Values presented are item response probabilities (0 = minimum probability of preferring confidentiality/consent, 1 = maximum probability of preferring confidentiality/consent). For region and education, odds ratios are presented. Class 1 is reference class.

A further investigation of the model split by gender (see Table A1) showed that men and women mainly differed with regards to Class 3 and 4. For men, Class 3 (5% of all men) represented positive views on confidentiality but negative views on consent, Class 4 (26%) represented positive views on confidentiality and consent. For women, Class 3 (27% of all women) represented fairly positive views on both confidentiality and consent, and Class 4 (11%) held the same pattern but to a more extreme extent. Class 1 and 2 primarily mirrored those from the main LCA.

#### Discussion

When a decision has to be taken about the medical management of a pediatric case, the pediatric patients, their parents, and their physicians are confronted with uncertainty due to tradeoffs between the variability of a disease course, effectiveness of the treatment, possible side effects and possible comorbidities (Fiks & Jimenez, 2010; Ford et al., 2016; Lipstein et al., 2012). Physicians will strive to minimize these possible adverse decision outcomes (which could lead to decisional regret) and to maximize high-quality decisions, which are shared and balanced i.e., in line with the families' values (both parent's and child's) and if possible with the local societal and cultural values (Charles et al., 1999; Lipstein et al., 2012; Park & Cho, 2018). In older children or adolescents, this shared decision-making could result in less input from the parents in favor of more input from the child. As the available literature on this topic is scarce (Lipstein et al., 2012; Park & Cho, 2018), with most existing studies set in the United States and utilizing a qualitative methodology, we set out to study the parental perspective on health-related confidentiality and consent for adolescents with a case-based questionnaire in Belgium and The Netherlands. We asked participants to answer according to their own opinion – not what they believe is legally required – regarding medical decisionmaking in minors.

Our findings indicate that the majority of Belgian and Dutch parents in the sample are not in favor of leaving confidentiality with the adolescent in all cases. This is in line with research that showed that parents, even though they agree with some of the benefits associated with confidential care, also want to be informed about important information or the medical decisions, even if it is specifically requested that they should not be informed (Duncan et al., 2011; Sasse et al., 2013). This challenges the model of shared decision-making (Lipstein et al., 2012), as two of the parties in this model (patients and parents) appear

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seemingly in conflict with one another with regards to confidentiality in most of the cases under study. Although often perceived as the ideal medical decision-making model for minors, the model may be more appropriate for young children rather than adolescents. The latter's growing desire for autonomy and ability to make decisions leaves the role of parents in doubt: where does their parental responsibility end, and where does their trust begin? Views on confidentiality were found to differ significantly by educational attainment. Highly educated respondents are more likely to leave confidentiality with the adolescent. This is somewhat surprising as previous research points out that higher educated people prefer to be informed about their own and their children's healthcare situation (Cullati et al, 2011; Dadlez et al., 2018). However, findings regarding the role of parental education (or socioeconomic status (SES) more generally) are rather mixed, as other studies have shown that parents with high SES are less controlling than low SES parents, which is in line with the findings of the current study (Harvey et al., 2016; Li et al., 2000). In a review of the literature, Hoff et al. (2002) found that low SES-mothers tend to become more authoritarian and aimed at maintaining order and obedience over their children, while high SES-mothers value selfdirection and individual autonomy for their children.

Regarding the views on consent, participants tend to follow the adolescent's preference. The majority of respondents would allow the maxillofacial surgery and the migraine medication, while they would not allow the adolescent to stop taking ADHD medication. Unlike the findings regarding confidentiality, where the link between parents' educational attainment and preferences was clear, results regarding consent are mixed. On the one hand, highly educated parents are more likely to support not taking the ADHD pills that are prescribed, but are less likely than lower educated respondents to support the maxillofacial surgery. This echoes the sentiment from previous findings on education: not taking the ADHD pills can be interpreted as supporting a return to the adolescents 'true self' – in line with high SES-mothers' value of self-direction and autonomy (Hoff et al., 2002) – while the maxillofacial surgery can be interpreted as a way to physically alter (and thus, reject) the true self. These mixed results align with research that showed that surveyed parents often disagreed with their children about decision-making and treatment preferences (Hankins et al., 2007).

Next we classified participants who gave similar answers in groups using latent class analysis. This resulted in four different classes of respondents, with each class holding a

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different perspective on medical decision-making in minors. In constructing these classes, we noted a similarity between the four proposed classes and Baumrind's (1989) and Maccoby and Martin's (1983) often-used typology of parenting styles, based on the parenting dimensions of responsiveness (support) and demandingness (control). Many subsequent studies have shown that these dimensions combine into four distinct parenting styles: authoritarian, authoritative, permissive, and neglectful (Power, 2013). Respondents in class 1, which represents 20% of parents, held negative views towards both confidentiality and consent. This may reflect of the authoritarian parenting style, in which parents report a high degree of control over their child. The permissive parenting style, in which parents focus on the autonomy of their child by providing a high degree of support but low control, represents the opposite view in Baumrind's model. This may apply to class 2, representing 45% of the current sample, in which respondents valued consent (autonomy), while not valuing confidentiality (control).

Baumrind (1989) describes an authoritative or democratic parenting style in which parents can discuss (health-related) issues openly and support their child. This style could match class 3, in which parents assign both confidentiality and consent to the adolescent. The difference between authoritarian and authoritative styles lies in the multidimensional feature of 'control'. The authoritarian style represents the 'direct' control with threats and commands. The authoritative style represents a more 'supportive' control with recommendations and encouragement (Power, 2013). Finally, Baumrind (1989) describes a neglectful parenting style which was later described as an uninvolved style by Maccoby and Martin (1983). While we did not find direct evidence for this style in our results, it could be argued that class 3 – in which respondents held positive views towards confidentiality and consent – may also reflect to this parenting style: parents have no interest in knowing what was discussed with a physician, nor do they want to interfere with their child's wishes. This could be seen as supportive, but may also represent a lack of interest in the child's wellbeing.

#### Ethical and practical considerations

Although the model of shared decision-making for minors implies key roles for physician, parents, and patient, the results from our study – but also of other studies (Carlisle et al., 2006; De Coninck et al., 2021; Sasse et al., 2013; Song et al., 2019) – indicate that the wishes of patients and parents regarding medical treatments sometimes clash. Although legislation

in most countries ensures that adolescents have a host of patient rights that protect their confidentiality and degree of autonomy (Devroey et al., 2013), it remains important for intrafamilial cohesion and well-being to provide everyone with agency when deciding on medical treatments for minors. Assent may be key in achieving this (Kuther, 2003). The assent process would involve an interactive process between minors, parents and physicians that "involves developmentally appropriate disclosure about the illness, and solicitation of the minor's willingness and preferences regarding treatment. This commonly accepted definition of assent as a minor's agreement to participate sets a lower standard of competence than informed consent because it does not require the depth of understanding or the demonstration of reasoning ability required for informed consent" (Kuther, 2003, p. 351). Although parents often have a legal responsibility to make decisions on behalf of their children, Kunin (1997, p. 44) also describes a "moral and ethical need to respect the rights and autonomy of every individual, regardless of age". By promoting developmentally appropriate participation in shared decision-making, adolescents will feel like they are taken seriously rather than simply being heard by parents and physicians (Melton, 1999). This may help in bringing all three parties together by respecting ethical principles of autonomy, while at the same time supporting minors with opportunities to exercise growing levels of independence though discussion and 'genuine' shared decision-making.

#### *Limitations of the study*

Throughout the research process, we identified some limitations of the study. An initial limitation concerns our use of vignettes. Although casuistry remains a methodology that is often used in medical ethics and has some advantages (Spielthenner, 2016), it also has a number of shortcomings (Rubeis & Steger, 2017). Casuistry often requires a social consensus to decide the paradigm case. For example, it could be argued that being in favor of confidentiality for adolescents is considered to be the social consensus in the confidentiality cases. However, contemporary postmodern societies are characterized by various moral viewpoints that make it very difficult to talk about such a social consensus (Rubeis & Steger, 2017; Spielthenner, 2016). The participants' personal moral intuitions may also be important drivers of their responses to the cases. However, critics of this idea have observed that moral intuitions can be incorrect, with actual behavior deviating from the preferred choice in the case (Arras, 1991; Rubeis & Steger, 2017). Secondly, the questionnaire lacks important healthrelated information. Other indicators such as the health status of the respondents, as well as the age, gender and health status of their children and previous negative experiences with medical decision-making were not included in our data. Thirdly, we did not assess parenting style. Therefore, we are very careful with our post-hoc interpreting and assigning our participants in general to a specific parenting style based on their answers. Furthermore, we cannot make any claims regarding the direction of the associations found given the fact that we are working with cross-sectional data.

#### **Recommendations for further research**

There are a number of changes that we would like to suggest for further research. Firstly, as mentioned above, our questionnaire lacked several variables that could be of interest: previous life events, parenting styles, and health issues are elements that should be considered for inclusion in future studies on these topics. We also did not have information regarding the children of participants (e.g., age, gender). Parents of young children may react differently to the cases than parents of older children, for example because parents of young children have not yet had to cope with any of the topics discussed in the cases.

Secondly, different modifications of the cases could be an interesting area for further research. As mentioned above, the set-up of some cases needs to be reconsidered. Parents need to be able to empathize or perhaps even recognize themselves in the case. Furthermore, it might be interesting to experiment with different types of cases. For example, comparing cases on decisions that have a long-term impact versus one-time interventions. Treating an STD is a one-time intervention. On the other hand, prescribing testosterone to induce puberty is a medical treatment that could have long-term effects. Aside from changing the type of intervention, changing the specialist could also influence the answers. In our preceding qualitative pilot study (Stavleu et al., 2022), participants pointed out that they would respond differently to family than to an emergency physician (Duncan et al., 2011).

Furthermore, it could be helpful to inform parents about the legislation on medical decision-making in minors. Our results indicate that parents often are not unequivocally in favor of confidentiality and consent among adolescents. By implementing e-learning in advance of the questionnaire, we could exclude the hypothesis that parents' lack of knowledge about the right to privacy is the reason why they want to be informed (even when children have reached a certain age). Future studies could also focus on the opinion of

healthcare workers or the adolescents instead of the parents – the other two parties in the shared decision-making model. It has been shown that especially female and older adolescents highly value their privacy during medical consultations (Carlisle et al., 2006; Gilbert et al., 2014).

Finally, the legislation regarding this topic differs in many European countries. Our current findings are reasonably similar in Belgium and The Netherlands. This is not entirely surprising as these two neighboring countries are culturally similar (Vromans et al., 2013), despite using a different system to assess a minor's competence to make autonomous treatment decisions (physician assessment versus age limit). Although Dutch participants appear to be somewhat more supportive of adolescents' confidentiality than Belgian respondents, responses on consent were highly similar. With this in mind, further elaboration and comparison of different European perspectives could reveal important insights.

#### Conclusion

Our study shows that Belgian and Dutch adults are more inclined to grant autonomy to the adolescent in cases regarding consent than in cases regarding confidentiality. They are willing to let an adolescent make medical decisions, but only to a certain extent. These overall findings are consistent with the results of our latent class analysis, in which responses of nearly half of all parents appear to indicate the possibility of an authoritative or democratic parenting style. In this approach, parents want to be informed to advise and help their child to make the correct final decision. A questionnaire on parenting styles prior to the cases could strengthen this evidence in future research. Furthermore, the multivariate analysis revealed novel insights on the role of gender and educational attainment. These two variables seem to play a significant role in parents' reactions to the cases. Men were more eager to be informed about the depressed mood of their adolescent and were more conservative regarding ADHD treatment than female respondents. Furthermore, although it is described that higher educated parents are more interested in the health of their adolescent, this was not always the case in our findings.

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## **Conflict of interest**

The authors declare no conflicts of interests.

## Data availability

The full dataset is available in De Coninck et al. (2022).

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## Appendix A

## Cases on clinical decision-making in adolescents

Imagine that you are the mother/the father of a fifteen-year-old teenager. Try to read the following cases from that perspective. For this questionnaire we assume you are the biological parent of the teenager.

## **Confidentiality**

#### Case 1

Your daughter has had a recent relationship and has an unpleasant problem. The GP diagnosed her with a sexually transmitted disease (STD) that can easily be treated without side effects. She asks the doctor to not inform you about this infection.

Which decision do you think the doctor should take?The doctor reports the infection to the parents.The doctor **does not** report the infection to the parents.

## Case 2

This week, you have received a hospital bill for an abdomen ultrasound that has been performed on your son. You ask him why this examination was performed, but your son does not want to tell you this. You contact the GP who ordered the ultrasound and ask him for the reason of the examination.

Which decision do you think the doctor should take? The doctor reports the reason for the ultrasound to the parents. The doctor **does not** report the reason for the ultrasound to the parents.

## Case 3

Over the past few weeks, you have noticed that there is a problem with your daughter: she is not sleeping well, spends time sitting alone in her room, does not talk to her girlfriends anymore, is often in a depressed mood and is not eating well. You are worried that she is depressed or even suicidal. You know that your daughter went to see the GP about this concern a few days ago, but you do not know what was discussed during the consultation.

Which decision do you think the doctor should take?

The doctor reports the presence of depression or suicidal ideation to the parents. The doctor **does not** report the presence of depression or suicidal ideation to the parents.

## **Consent**

#### Case 4

You and your daughter consult the GP due to problems at school. At the latest parents' evening, there were a few comments about disruptive behavior in class. Furthermore, her grades on her latest school report are worse than last year's. Your daughter has ADHD (attention-deficit hyperactivity disorder) and she has been taking drugs over the past few years to improve her concentration with good effect on behavior and grades. However, she reports to the GP that she does not want to take these drugs anymore because she feels restrained by them. You realize the importance of good grades for the future of your daughter.

Which decision do you think the doctor should take? The doctor prescribes the medication and explicitly asks you daughter to take them. The doctor **does not** prescribe the medication.

#### Case 5

Your daughter has an appointment with the mouth and jaw specialist concerning her teeth. She has got a special position of her lower jaw: a mandibular prognathism. Her lower jaw is positioned too far backwards and because of this she is bullied by her peers. The orthodontist explains that the only way to put her teeth completely in the correct position is a surgical procedure in which her lower jaw is sawn through. Her appearance is very important to her, and she insists that she wants the surgery to be performed. She hopes that it will bring an end to the bullying. You – as her parents – think, however, that she looks fine the way she is, and you think the surgery is dangerous and unnecessary.

Which decision do you think the doctor should take? The doctor performs the operation. The doctor **does not** perform the operation.

#### Case 6

Your son has been suffering from migraines for about a year now and the migraines occur about three times a month. He would like to do something about it, because the severe headaches are an impediment for attending school, sports and hobbies. Your GP proposes a drug therapy to reduce the headaches, but this medication sometimes has side effects. Your son thinks this is a good solution and he would like to try it. You, however, think that a fifteenyear-old should not be taking long-term medication, and you do not agree with this treatment. Unfortunately, there are no other effective treatments available.

Which decision do you think the doctor should take?

The doctor prescribes the medication.

The doctor **does not** prescribe the medication.

	Class 1		Class 2		Class 3		Class 4	
	Male	Female	Male	Female	Male	Female	Male	Female
Case 1 (STD)	.20	.25	.13	.23	.64	.78	.86	.98
Case 2 (Ultrasound)	.00	.01	.05	.02	.83	.68	.76	.81
Case 3 (Depressed mood)	.00	.05	.08	.08	.85	.79	.77	.86
Case 4 (ADHD)	.37	.40	.16	.33	.59	.78	.39	.00
Case 5 (Maxillofacial surgery)	.41	.00	.87	.88	.00	.61	.74	.81
Case 6 (Migraine)	.37	.35	1.00	.89	.00	.69	.87	.96
Share of participants per class	.19	.14	.49	.49	.05	.26	.27	.11

Table A1. Latent Class Analysis on parental perspectives on confidentiality and consent by gender

Note: Values presented are item response probabilities (0 = minimum probability of preferring

confidentiality/consent, 1 = maximum probability of preferring confidentiality/consent).