Are Parents Informed Well Enough About Their Child's Long-term Risks Related to Undescended Testis?

Worldwide, recommendations for timely surgical repair of undescended testis (UDT) are not well translated into clinical practice, potentially due to suboptimal patient/parent education. We evaluated the frequency and content of information provided to affected parents of 310 consecutive cases of UDT undergoing orchidopexy. Parents were enquired regarding details of education provided by the attending clinician. 18% of parents were not provided with detailed information regarding any long-term consequences of untreated UDT. In the 79% who were educated, information about impaired fertility was frequent, while malignant degeneration, hypogonadism and testicular atrophy were poorly communicated. 49% of all parents searched for further information on the internet or through a second medical opinion. The frequency and level of detail of information regarding long-term complications provided to parents of children with UDT is suboptimal and needs to be improved.

Key words: Cryptorchidism, Infertility, Testicular cancer.

Trial registration: German Clinical Trials Register, DRKS00015903.

Undescended testis (UDT) is among the most common reasons for pediatric surgery worldwide. Untreated, UDT features a risk for various long-term sequelae, including testicular cancer of UDT and impaired testicular growth and functionality, atrophy and even infertility. Additionally, there is evidence for UDT-associated hypogonadism.

To avoid these complications, international clinical guide-lines recommend early surgical orchidopexy, usually at 12 to 18 months of age. However, this goal is currently only achieved in a small proportion of affected patients [1]. Late orchidopexy in children with UDT seems to have several underlying causes viz., suboptimal knowledge regarding clinical guidelines, secondary UDT (which mostly occurs later in childhood), referral delay, parental reservations, and others [2]. The aim of this study was to analyze the frequency and quality of medical information regarding long-term risks of UDT provided to affected parents by their physicians.

This study was performed at six urology/pediatric surgery departments in Germany between April, 2016 and June, 2018. We prospectively analyzed 310 consecutive cases of boys with UDT undergoing orchidopexy. All children had initially been diagnosed and referred by the treating primary care pediatrician.

Parents were interviewed anonymously using a question-naire prior to the surgical intervention of the children. A significant language barrier was an exclusion criteria for the study. Specifically, we inquired details of UDT-specific medical education and informed consent provided to the parents by the attending clinicians, and also asked whether and how parents tend to search for further information on UDT-related medical risks. The inclusion and exclusion criteria have been previously described in detail [2]. Statistical analyses were performed using SPSS version 23 (IBM Inc.). The *P*-value was calculated using the Chi-square test.

We enrolled 310 boys with a median (IQR) age of 27 month

(14-60) (**Table I**); 18% (n=56) of the patients' parents were not provided with detailed information regarding any long-term consequences of untreated UDT. In the 79% (n=244) who were educated, information about impaired fertility was frequent (95%, n=230), while malignant degeneration (64%, n=156), hypogonadism (40%, n=96) and testicular atrophy (2%, n=4) were poorly communicated. The median time lag between the pediatricians' initial diagnosis and surgical treatment was 2 month.

Forty-nine percent of all parents (n=153) searched for further information after their consultation, mostly on the internet (76%; n=117) or through a second medical opinion (17%; n=26). Specifically, primarily provided information about UDT-related risks led to a significantly increased interest in obtaining further information after the consultation (P=0.03). Interestingly, delayed surgery (>12 months) did not lead to more frequent risk information (P=0.45) or to a higher motivation to search for further information (P=0.35) as well as a diagnose-treatment-delta of more than two months (P=0.22 and P=0.35, respectively). Of all utilized internet resources, Google was used much more frequently than social networks, and mobile devices were more popular than desktop computers (Web Fig. 1). When assessing the quality of the acquired additional information, the most commonly used source (internet) was rated the worst (score 2.2), while medical journals were rated most helpful (score 1.7), on a scale from 1-5 by the parents (Fig. 1).

The degree of suboptimal education reported in this study at 19% was surprisingly high. Further, parents who were edu-cated about UDT risks mostly received incomplete information, which is concerning as the risks of UDT are serious [3-7]. Niyogi and Clarke have demonstrated distinct differences in opinion between patients and surgeons about the information to be provided before surgery [8]. These included the level of expertise of the surgeon as well as the risk of complications. Several studies have shown that parents' experience of information flow regarding their child's surgery may vary. Similarly, when obtaining informed consent for clinical

 Table I Characteristics of Children With Undescended

 Testis (N=310)

Characteristics	Value
Preterm birth	129 (43)
Pre-existing conditions	76 (25)
Regular medication	46(15)
Malformation	35 (18)
Primary undescended testis (pUDT)	103 (33)
pUDT one-sided	58 (56)
pUDT both sides	35 (34)
pUDT side unknown	10(10)
Acquired undescended testis	104 (34)
Unknown testicular position	103 (33)
Surgery in time (≤12 mo)	53 (18)
Age at UDT diagnosis (mo) ^a	24 (11-48)
Age at surgery $(mo)^a$	27 (14-60
Time from diagnosis to therapy (mo) ^a	3 (1-7)
Conservative treatment prior to surgery	17 (51)

Values in no. (%) or ^amedian (IQR).



Fig. 1 Frequency and content of provided Information regarding UDT risks (top); Further information-seeking behavior of parents of boys with undescended testis undergoing orchidopexy (bottom). This illustration shows how frequently And where further UDT information was obtained by the parents and how the Information quality was rated (range 1 [very good] - 5 [very poor]).

research in children, there is a discrepancy between parents' evaluation of the adequacy when being educated and evaluation of specific understanding or even memorization [9]. In this sense, the main limitation of this study is the fact that parents were asked whether and to what degree they were informed about UDT risks by their physicians. Hence, some uncertainty about miscommunication or even forgetting of discussed matters may have occurred. On the other hand, this study well reflects the degree of information that was finally retained by the affected parents, and demonstrates the need for improvement regarding patient/parent communication. As a modern way to improve patient/family education, the use of internet and social media campaigns e.g., for children with UDT, has proven to be a promising strategy [10].

Importantly, the assessed cohort was sampled at the point of registering their child for orchidopexy in urology/pediatric surgery departments. Hence, the decision to go ahead with surgery had already been made. In other words, if parents who agree to surgery are improperly informed, it is not far-fetched to reason that parents of boys with UDT who are not planning for surgery will at least be equally informed, if not even less. Consequently, clearer communication of long-term UDT risks and tailoring the flow of information to the specific needs of affected families may help to overcome the dilemma of late orchidopexy in boys with UDT.

Further information was sought by parents who received at least some initial information regarding UDT risks by their physician, demonstrating the positive effects of informing families to empower them towards taking control of their own health rather than being steered purely by their doctors.

Medical professionals treating children with UDT should

make an effort to thoroughly inform affected parents about longterm complications of UDT. This may be an important step towards minimizing the widespread UDT treatment delay and towards earlier diagnosis and treatment of long-term sequelae.

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Web Fig. 2 Information-seeking strategies of involved parents regarding medical context.