

## Predictors of delayed consultation in undescended testis patients at a Rwandan referral hospital

**Authors:** A. Bonane<sup>1,2,\*</sup>; A. Nshimiyimana<sup>1</sup>; I. Nzeyimana<sup>3</sup>; A. Nyirimodoka<sup>1</sup>, E. Muhawenimana<sup>2</sup>; T. Hategekimana<sup>2</sup>; Jennifer Rickard<sup>1,2,4</sup>

**Affiliations:** <sup>1</sup>Department of Surgery, University of Rwanda; <sup>2</sup>Department of Surgery, University Teaching Hospital of Kigali; <sup>3</sup>Department of Surgery, University Teaching Hospital of Butare; <sup>4</sup>Department of Surgery, University of Minnesota

### ABSTRACT

**INTRODUCTION:** Delayed management of undescended testes (UDT) is associated with an increased risk of malignancy and impaired fertility. To identify causes of delayed consultation of patients with UDT at a Rwandan referral hospital

**METHODS:** This was a retrospective study of patients with delayed UDT presentations from 2012 to 2016. A delayed UDT presentation was defined as any patient presenting with UDT at >1 year of age.

**RESULTS:** There were 44 cases of delayed UDT presentations. Most patients (n = 35, 79.5%) were born at a hospital; the rest (n = 9, 20.5%) were born at home. The patient's parent with higher education in the family was considered. Most of the patients' parents (n = 29, 65.9%) had a primary education, 6 (13.6%) had a secondary education (high school graduate), 1 (2.3%) had a university education, and 8 (18.2%) never went to school. The reported reasons for delays as they appear in the patient chart were 16 (36.4%) patients due to ignorance, 12 (27.3%) due to poor physical examination at birth, 7 (15.9%) due to poor guidance, 4 (9.0%) due to poverty and 5 (11.4%) due to long appointments. There were no overlapping reasons for delay reported. Patients born at home were more likely to identify ignorance as a reason for the delay (p = 0.007). Of the 16 patients who reported a delay due to ignorance, 12 of their parents had primary education, and 3 had no education. Most (n = 34, 77.3%) patients were fertile in adulthood, but 9 (20.4%) presented with infertility and 1 (2.3%) presented with testicular torsion.

**CONCLUSION:** A number of reasons are responsible for delayed consultation in patients with UDT, including ignorance, poor physical examination, poor guidance, and poverty. Most of the causes are preventable. The urgent need for awareness of UDT and collaboration between physicians is paramount for early consult and management.

**Keywords:** Cryptorchidism, Rwanda, Retrospective Studies, Referral Consultation

**\*Corresponding author:** Alexis Bonane, Department of Surgery, University of Rwanda, College of Medicine and Health Sciences, University Teaching Hospital, Ministry of Health, Kigali, Rwanda. Email: alexbonane2015@gmail.com; **Potential Conflicts of Interest (Col):** All authors: no potential conflicts of interest disclosed; **Funding:** All authors: no funding has been sought or gained for this project; **Academic Integrity.** All authors confirm that they have made substantial academic contributions to this manuscript as defined by the ICMJE; **Ethics of human subject participation:** The study was approved by the local Institutional Review Board. Informed consent was sought and gained where applicable; **Originality:** All authors: this manuscript is original has not been published elsewhere; **Review:** This manuscript was peer-reviewed by three reviewers in a double-blind review process; **Type-editor:** Anna (USA).

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## INTRODUCTION

The testes are a specialized pair of organs that produce spermatozoa and androgenic hormones. By the 35th to 40th week of gestation, they descend from the intra-abdominal region into the scrotum, where they function optimally at 33°C, 3-4°C less than core body temperature. Testes located in the inguinal canal or abdomen are exposed to higher temperatures with consequent progressive alteration in morphology and physiologic functions as well as an increased risk of complications [1]. Undescended testes (UDT) present at a rate between 3 to 5 % in term male babies. This rate is reduced to 1% when the child reaches 6 months to 1 year of age due to spontaneous descent during the first year of life. In comparison, the prevalence increases to 33% in premature babies [2].

The exact causes of failure to descend is not well understood, but there are possible risk factors, including prematurity, low birth weight, smaller size fetus for gestational age, twins, and exposure to estrogen in the last trimester [3]. Mullerian-inhibiting substance (MIS) is a gonadal hormone that causes the regression of the Mullerian ducts, the embryonic structures that give rise to the female genitalia, in male fetuses. MIS is important in the descent of gonads through the internal inguinal ring. In contrast, exposure to high concentrations of prenatal gubernacular growth factor and estrogen disrupts testicular descent [4]. Other factors also shown to increase the incidence of UDT include exposure to endocrine-disrupting chemicals like pesticides or diethylstilbestrol and abdominal defects like gastroschisis, omphalocele, cloacal extrophy, and prune belly syndrome; abdominal defects can affect the abdominal pressure needed to move testes toward the scrotum between 23rd and 36th weeks of gestation.

Early treatment for UDT is recommended. International guidelines recommend surgery (orchidopexy) between 6 and 18 months of age. The Swiss, Nordic and European Association of Urology/European Society for Paediatric Urology guidelines recommend an ideal deadline of 12 months, with 18 months being the latest [7-9]. These recommendations are based on evidence suggesting an increased risk of testicular malignancy and impaired fertility later in life associated with later or no treatment.

Despite the recommendations, the guidelines are often not achieved [10-12]. A study done at Sudan Teaching Hospital found that of the 61 patients who consulted with UDT, 44% presented after 24 months. In a study from Nigeria, orchidopexies were performed before age 2 in only 11% of patients with UDT [8]. In the same study, 42% of the orchidopexy cases were performed before age 5, and 58% were performed after age 5. Many other studies also found delayed operations. A study from Lagos University Teaching Hospital (LUTH) found that the median age at operation of their participants with UDT, age 1 to 11 years, was 3 years [9]. A Tanzanian study found that 50% of its patients presented for orchidopexy after 5 years of age [10]. Finally, a study from the United States reported that the mean age at consultation for UDT was 20.3 months and for surgery was 28.9 months [11].

Causes of delayed presentation of UDT are variable. In Sudan, the causes included ignorance, poor follow up, and a lack of healthcare facilities [3]. A study from India identified common causes for late consultation in patients with UDT included ignorance (9%), and shyness (42%) [12]; other patients delayed seeing a physician because they consulted traditional healers first or had poor guidance.

Despite the many causes discussed, there is currently no data in Rwanda concerning the causes of delayed UDT consultations. Therefore, the aim of this study is to identify the causes of delayed consultation in patients with UDT presenting to a tertiary referral hospital in Rwanda.

## METHODS

This is a retrospective descriptive study of patients with a delayed presentation to the Urology Unit of the University Teaching Hospital of Kigali (CHUK) for UDT from January 2012 to January 2016. We defined delayed presentation of UDT as any patient with UDT presenting to the CHUK Urology unit at greater than 1 year of age.

CHUK is a national tertiary referral hospital located in the centre of Kigali, the capital city of Rwanda. The hospital serves a catchment area of approximately 6 million people and has a surgical department that actively pursues clinical and

academic activities. The Urology unit consists of 3 urologists working 5 days a week, seeing an average of 180 patients each week.

Patients' identification numbers were obtained, and their files were retrieved from the archives. Relevant data, including patient demographics, the reason for consultation, level of education (of the parents), and reasons for delayed consultation, were extracted from patients' files. Data on complications like infertility and testicular torsion were also collected. Infertility was defined as failure to impregnate following a year of unprotected sex and azoospermia on semen analysis.

The Reasons for delayed consultation were organized thematically and categorized as missed diagnosis, poor guidance, ignorance, poverty or long appointment [12,13]. Missed diagnosis is defined as cases where the diagnosis was not made at birth. Cases where the diagnosis was made but the patient was not referred or managed were categorized as poor guidance. Ignorance was defined as the mother's lack of information about the right time of orchidopexy. Instances of financial challenges limiting treatment or referral were inputted under poverty. Long appointments were any instances where treatment or management was late due to delayed appointment scheduling. Data was entered into EPI-DATA and then exported to SPSS (version 16.0). The analyzed data were reported as frequencies and percentages. The Chi-square test was used to determine the association between variables and reasons for delayed consultation.

The ethical research committee of CHUK approved this study, and the ethical approval reference number is ECCHUK/413/2017.

## RESULTS

During the study period, 87 patients consulted CHUK Urology Unit for UDT. Among the 87 patients with UDT, 22 (25.3%) consulted before one year of age, 21 (24.1%) had incomplete files, and 44 (50.5%) consulted after 1 year of age (delayed UDT presentation).

Of the 44 patients with delayed UDT presentation, 19(43.2%) presented with unilateral left UDT, 9 (20.5%) with right UDT, and 16 (36.4%) with bilateral UDTs. Sixteen (36.4%) of these patients were from Kigali city, 11 (25.0%) were from Eastern Province, 10 (22.7%) were from Northern Province, 4 (9.1%) were from Southern Province, and 3 (6.8%)

were from Western Province (Table 1). Most (n = 29, 65.4%) of the patients' parents had a primary education, 6 (13.6%) had a secondary education, 1 (2.3%) studied at university and 8 (18.2%) were illiterate.

The majority (n = 35, 79.5%) of the patients with delayed presentations were born at the hospital. Only 9 (20.5%) patients were born at home. Many parents (n = 20, 45.5%) noticed the condition at birth, while other parents and or patients noticed the condition later on; 9 (20.5%) before the age of 2, 7 (15.9%) between ages 2 and 6 (13.6%) between ages 6 and 10, 1 (2.3%) between ages 11 and 15, and 1 (2.3%) at age 26. Eight (1.2%) patients consulted with urology before the age of 2, 9 (20.5%) between ages 2 and 5, 11 (25%) between ages 6 and 10, 5 (11.4%) between ages 11 and 15, 2 (4.5%) between ages 16 and 20, 4 (9.1%) between ages 21 and 25, and 5 (11.4%) at age 26 and older.

While some patients with delayed UDT presentations had complications, most (n = 34, 77.3%) presented without complications. Of the patients with complications, 9 (20.5%) presented with infertility, and 1 (2.3%) presented with testicular torsion. Of the 9 cases with infertility, 4 patients were between ages 21 and 25, and the remaining 5 were age 26 or older. The patient with testicular torsion was 27 years old.

Sixteen (36.4%) of the patients reported ignorance as the reason for the delay. Other reasons reported included missed diagnosis at birth (n = 12, 27.3%), poor guidance (n = 7, 15.9%), long appointments (n=5, 11.4%) and poverty (n = 4, 9.1%) (Table 2). There was an association between home birth and ignorance as the provided reason for the delay (p = 0.007). Patients born at home are more likely to identify ignorance as the reason for delayed presentation. Among the 16 patients who reported delay due to ignorance, 1 parent had a secondary level of education, 12 had a primary level of education, and 3 did not have an education.

The breakdown of parents' educations was also analyzed for other reasons. Of the 7 patients who reported poor guidance, 6(85.7%) parents had primary education, and 1 (14.3%) had no education. Among the 5 patients with long appointment times, 1(20.0%) parent had a university education, 3 (60.0%) had a secondary education, and 1(20.0%) had a primary education. Of the 4 patients who reported poverty, only 1 (25.0%) parent had primary education while the

**Table 1: Patient characteristics**

		Frequency	Percent
Place of origin	Kigali	16	36.4
	Eastern province	11	25.0
	Northern province	10	22.7
	Western province	3	6.8
	Southern province	4	9.1
Place of birth	Hospital	35	79.5
	Home	9	20.5
Parent's education level	Primary	29	65.9
	Secondary	6	13.6
	University	1	2.3
	None	8	18.2
Diagnosis	Unilateral, left undescended testis	19	43.2
	Bilateral undescended testes	16	36.4
	Unilateral, right undescended testis	9	20.5
Age at first awareness of diagnosis by patient/parent	At birth (<1 year)	20	45.5
	1 to 2 years	9	20.5
	2 to 5 years	7	15.9
	6 to 10 years	6	13.6
	11 to 15 years	1	2.3
	15 years	1	2.3
Consulted other health facility	Yes	9	20.5
	No	35	79.5
Age at urology consultation	1 to 2 years	8	18.2
	2 to 5 years	9	20.5
	6 to 10 years	11	25.0
	11 to 15 years	5	11.4
	16 to 20 years	2	4.5
	21 to 25 years	4	9.1
	26 years	5	11.4
Reason for delay	Ignorance	16	36.4
	Missed diagnosis	12	27.3
	Poor guidance	7	15.9
	Long appointments	5	11.4
	Poverty	4	9.1
Complications	None	34	77.3
	Infertility	9	20.5
	Testicular torsion	1	2.3

remaining 3(75.0%) had no education. Lastly, for the 12 patients who were delayed due to missed diagnosis at birth, 2 (16.7%) of the parents had a secondary education, 9 (75.0%) had a primary education, and 1 (8.3%) had no education. All the patients who had complications reported ignorance or missed diagnosis as the reasons for their delayed presentation.

consulting doctor and midwives. A different study from India studying reasons for late consultations in patients with UDT also found ignorance as one of the reasons; in their patient sample, 9% reported ignorance and 42% reported shyness as the reason for delayed UDT presentation [12]. With ignorance repetitively reported across several studies as a cause for delayed UDT presentation, it is evident that greater educational measures about UDT is needed.

**Table 2: Histological characteristics**

		Reason for Delay					P-value
		N (%)					
		Ignorance N= 16	Missed diagnosis N= 12	Poor guidance N= 7	Poverty N= 5	Long appointment N= 4	
<b>Place of origin</b>	<b>Kigali</b>	4 (25)	6 (50)	2 (29)	2 (50)	2 (40)	0.664
	<b>Outside Kigali</b>	12 (75)	6 (50)	5 (71)	2 (50)	3 (60)	
<b>Home birth</b>		8 (50)	0	1 (14)	0	0	0.007
<b>Parent's education level</b>	<b>None</b>	3 (19)	1 (8)	1 (14)	3 (60)	0	0.019
	<b>Primary</b>	12 (75)	9 (75)	6 (86)	1	1 (25)	
	<b>Secondary</b>	1 (6)	2 (17)	0	0	3 (75)	
	<b>University</b>	0	0	0	0	1	
<b>Complications</b>		8 (50)	2 (17)	0	0	0	

**DISCUSSION**

About half (n = 48, 50.6%) of all UDTs presenting to CHUK between January 2012 and January 2016 were delayed presentations and almost half of all patients with delayed UDT presentations noticed the condition at birth. Despite this, these patients did not immediately consult with a urologist. This suggests a failure in the healthcare system to adequately identify, educate, and refer UDT patients to receive proper care.

Overall, ignorance was cited as the most common reason for delayed consultations by 36% of patients. Some of these patients reported delaying their consultations because they thought their condition would resolve on its own in due time and or does not adversely affect them. Similar reports were noted in other studies. In a study conducted at Sudan Teaching Hospital, 44% of their 62 patients with UDT presented after age 2 [3]. The reported reason for the delays was ignorance of the initial

Many of these patients are delivered at home, so they may have limited interaction with the healthcare system. Community healthcare workers need to be educated to recognize UDT and may be called upon to play more proactive roles in these populations, like raising public awareness, to help minimize the risks of delayed identification and referral for UDT.

The local healthcare system can significantly impact the management and outcomes of patients with UDT. Several patients in this study had delayed presentation due to a missed diagnosis or poor guidance from healthcare workers. Missed diagnoses, poor guidance, and longer appointment times suggest a need for healthcare system improvements. A study from India showed that some patients with UDT presented to the hospital late because they consulted their traditional healers first and or had poor guidance [12]. Educating local healthcare workers (doctors, midwives, and

healthcare professionals) to identify and manage or refer patients with UDT to more adapt facilities within the first year of life is necessary. It is essential that healthcare workers understand and communicate to patients the importance of early consultation and treatment for UDT to minimize the risk of complications later in life. Currently, there are only 10 urologists in Rwanda, serving a population of 13 million. Efforts are underway to scale up the urologic capacity within the country to ease the burden of urological disease [14].

In addition to ignorance, financial reasons are also often cited as factors that impact when patients present for UDT [19,22]. Innovative ways to mitigate and minimize costs and improve patient access are vital. Most Rwandans have community-based health insurance. Without this insurance, patients or caretakers may delay their presentation to a local healthcare facility. Another commonly cited financial reason for delays is transportation costs [19]. To combat this barrier to care, some programs have incorporated travel vouchers to decrease costs to patients. More alternatives to increase the access and reach of surgical care are needed. One potential idea includes placing more surgeons at the district hospitals easily accessible to patients. Another idea is to develop more surgical outreach camps around the country for surgeons working in the major cities to volunteer a week operating at a more rural hospital. Currently, several surgical camps exist; these camps treat diagnosed UDT patients but do not spread awareness about the disease. Thus, there is a dire need for greater public health education and efforts to persuade patients with UDT to seek treatment earlier to reduce their complications risks.

Complications were present in 23% of our patients with UDT. These complications were experiences by patients who presented at an older age, as expected based on the types of complications associated with UDT. Fortunately, early identification and management of UDT has been shown to reduce complications such as torsion and infertility [24, 25]. The incidence of azoospermia in unilateral cryptorchidism is 13%. This figure increases to 89% in untreated bilateral cryptorchidism, making cryptorchidism the most common etiologic factor of azoospermia in adults [22]. Over the past decade, the rapid development of novel management approaches for male factor infertility

has enabled many of these men, previously believed to be infertile, the ability to become fathers [23]. Micromanipulation techniques, such as intracytoplasmic sperm injections applied to sperms and ova in vitro, allow sperms with the previously limited intrinsic fertilizing capacity to produce viable embryos [23].

This study has several limitations but provides important data on a delayed presentation for UDT in Rwanda. This study was performed at the largest tertiary referral hospital in Rwanda, serving a catchment area of approximately half of the Rwandan population. However, as a single-center retrospective study, there are limitations in the number of subjects and the generalizability of the data. The limited number of urologists in Rwanda serves as another limitation. With most urologists residing in the capital of Kigali, the patient population in this study may not represent the entire Rwandan population but does represent the majority of patients who trained specialists manage within the country. Therefore, this study does provide a perspective of the specialist care received by patients in Rwanda.

## CONCLUSION

Good physical examination at birth is the key to early diagnosis and proper management of UDT. With better patient education and referral to healthcare facilities, early consultations and hence timely management can be achieved. Greater efforts to increase population awareness of UDT and better collaboration between physicians and urologists in conducting newborn examinations are critical for timely consultations and treatments of UDT.

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