

## **TITLE PAGE**

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**Title:**

**“I am tired of the disease and eating too many medicines”: Seeking adolescent’s lived experiences about Chronic Renal Disease (CRD)**

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## **ABSTRACT**

**Background:** Chronic renal disease (CRD henceforth), results from a range of conditions that cause irreversible damage to the kidneys and is a recognised major medical problem worldwide. CRD in children and adolescent's is an enervating condition requiring lifelong treatment in order 'to survive'. Several researchers have criticised the research on children with CRD as most of these studies rely on standardised tools which seem to be grounded in objectivity and quantification.

**Methods:** In this milieu, this Indian study adopts a qualitative approach underpinned by the philosophy of Husserlian phenomenology with descriptive phenomenology as a method. The primary purpose of the study was to delve into the lives of adolescents suffering from CRDs to understand their perceptions about how this challenging condition affects and changes their lives.

**Results:** CRD is a chronic condition that confines the lives of these adolescents by demanding a major shift to more prescribed and restrictive lifestyle.

**Conclusion:** The lives of the adolescent participants conveyed a paradoxical nature in terms of suffering; struggling to cope with the stringent lifestyle changes and yet trying to be adapting to the disease to moving forward in life.

### **Keywords:**

Chronic renal disease, adolescents, phenomenology, lived experiences.

## INTRODUCTION

Chronic renal disease (CRD henceforth), results from a range of conditions that cause irreversible damage to the kidneys and is a recognised major medical problem worldwide.<sup>1</sup> Patients with CRD can progress to end-stage renal failure resulting in a severe and irrevocable reduction in renal function, which requires dialysis or renal transplantation to prevent death. Even when this does not occur; CRD's have an indirect impact on the global morbidity and mortality by increasing the risks associated with other major killer diseases like hypertension, cardiovascular disease, and diabetes mellitus.<sup>2,3</sup> Individuals who have CRD are at a 20% higher risk of cardiovascular complication than healthy individuals.<sup>4</sup> Thus, a higher number of individuals die from cardiovascular complications than have renal replacement therapy in the form of dialysis.<sup>5</sup>

The Global Burden of Disease (GBD) study 2015, ranks chronic renal disease as the eighth leading cause of death in India.<sup>3</sup> India does not have an established program to manage CRD, and even reliable data on the prevalence of CRD does not exist.<sup>6</sup> In the absence of any screening guidelines children suffering from the initial stages of CRD, which can determine the long-term prognosis of the condition, may not receive any medical attention. It is substantiated from a research from India in which 58% of children study participants with renal conditions directly presented with end-stage of renal disease.<sup>7</sup> This is suggestive of the fact that a substantial percentage of the pediatric CRD population develops renal insufficiency very early in life but may not receive medical attention. A similar study in Jamaican children helped document the aetiology and outcome of chronic renal failure in them. The results showed that half of the children participants were already in chronic renal failure at the onset of the study mainly due to delay in diagnosis of the renal conditions, which were easily treatable in early stages. The study concluded by stating that childhood CRD could be prevented by prompt investigation and appropriate treatment or referrals of relatively simple conditions like urinary tract infections (UTI) and glomerular nephritis (GN) by well-informed general practitioners.<sup>8</sup>

With no formal referral system in place in India, patients with CRD can go to any hospital across the country; however, care for such a condition is available mostly in higher-level tertiary hospitals. With a shortage in the number of publicly funded tertiary hospitals and a lack of health insurance, most patients are forced to seek highly expensive and economically unsustainable care at private hospitals. Lack of any government support to dialysis has prevented the development of ESRD (End-stage renal disease) registry in India.<sup>6</sup> The Indian healthcare scenario in the management of renal disease remains gloomy as less than 10% of all patients receive any kind of renal replacement therapy if required in advanced stages of the disease. Most patients starting haemodialysis die or stop treatment because of cost constraints within the first three months, very few can afford regular maintenance dialysis, and renal transplantation is often unavailable. Only about 2% of patients are started on peritoneal dialysis. About 5% of all patients with CRD end up having a transplant.<sup>9</sup> Children on long-term hemodialysis show a subnormal growth, poor quality of life and delayed sexual maturation. Hemodialysis is performed, 2-3 days a week, in the hospital as a daycare procedure. The procedure of hemodialysis is technically more difficult in children and requires close monitoring to prevent complications.<sup>10</sup>

CRD in children and adolescent's is an enervating condition requiring lifelong treatment in order 'to survive'.<sup>11</sup> Although CRD may not be considered numerically significant as compared to other common adolescent diseases, the health implications arising from it are profound.<sup>12</sup> Chronic illness in childhood and young people have huge social costs primarily because of the intensive treatment regimens limiting these children's involvement in school along with other activities and socialisation.<sup>13</sup> Other notable published studies document that children with CKD report worse physical and psychosocial health outcomes as compared to the general population.<sup>14,15</sup>

While more children are being treated for CRDs in recent years, research enhancing the understanding of their health and illness while dealing with such debilitating condition is still lacking.<sup>16</sup> With a major focus of research literature being on examining psychological aspects of coping with CRDs, the research areas to understanding the lives and experiences of such adolescents seem to be reluctant to extend beyond a 'medical' and 'psychological' bifurcation. Several authors have criticised the research on children with CRD as most of these studies rely on standardised tools<sup>17,18</sup> which seem to be grounded in objectivity and quantification<sup>19</sup> while lacking in areas exploring their health, sickness, and treatment-related experiences along with their perceptions about living with CRD. This gives a myopic view of the condition which primarily portrays a picture that the everyday management of this phenomena is just a linear process, whose locus lies within the adolescent patient and can be understood and measured by the mere usage of various scales and survey tools.<sup>13</sup> In this milieu, this study extends beyond the reductionist research strategies that value objectivity by attempting to understand the potential long-term impact that this disease creates. It required us to delve into the lives of such adolescents suffering from CRDs and understand their perceptions about how this challenging condition affects and changes their lives, which also remains the primary purpose of the study.

## **METHODS**

### **Research Design**

A qualitative approach underpinned by the philosophy of Husserlian phenomenology with descriptive phenomenology as a method was undertaken. The participant adolescents in this study ranged from 10 to 19 years of age. The participants belonged to rural districts of West Bengal namely, Bardhaman and Durgapur and the urban district of Greater Kolkata and the in-depth interviews were conducted at their respective homes (as per the participants convenience). The study was conducted between August 2014 and February 2015.

This method stands vital to understand a phenomenon as experienced by the participants in their lifeworld,<sup>20</sup> where the researchers bracketed engagement guided the findings. The relevance to the lived experience is that there is no dualist view, and the phenomenon is inextricably linked with the subject. This underpins the view that access to a phenomenon is through the participant.<sup>21</sup> The broader question that the researcher sought to get an understanding of was – What changes do adolescent's with CRD have to bring about in their lives? The researcher noted that there is enough information available about, 'What are CRDs?', 'What should patients suffering from CRDs do or avoid doing?', etc. To align with the philosophy of bracketing, the researcher consciously bracketed this information that was conceptualised during the phase of literature review, approaching the participants with an intent to investigate their experience as they lived with this disease. This desire for scientific

rigour underlies the use of bracketing technique for abstracting essences from lived experiences when doing descriptive phenomenology.<sup>22</sup> It is worth stating here that descriptive phenomenology seeks not to understand the ‘truth’ behind an experience (i.e. the experience as it occurs), but rather where the commonalities of how something is experienced intersect from the perspective of participants,<sup>23</sup> representing the universal essence of experience through the presentation of themes.

### **Engaging participants and the process of fieldwork**

It was a challenge to recruit participants as, India lacks data about patients suffering from CRDs and does not have a program to manage the renal disease conditions.<sup>24</sup> There is no formal referral system in place, and the shortage in the number of publicly funded specialised hospitals forces patients to seek care in expensive private hospitals.<sup>25</sup> As the study focused upon the adolescent’s suffering from CRD, participants were required to be from the age group of 10-19 years.<sup>26</sup> The participants were recruited from amongst the patients who attended outpatient departments within tertiary care private and aided hospitals in Kolkata. Nephrologists and general medicine consultants who treated nephrology patients were approached to provide contact details of the patients under their OPD care. On repeated requests and persistence, four city-based paediatric nephrologists and one general medicine practitioner who helped run the nephrology unit in an aided hospital agreed to share contact details of their patients. The clinicians identified certain adolescent patients as their regular patients who were suffering from CRD (patients in an advanced stage or end-stage were excluded from the research as CRDs many a time progress towards debilitating conditions). It was noted to consider the participants who were undergoing treatment for CRD for at least six months or more with the respective clinicians. It was felt that this criterion would help the researcher engage with participants, who were aware of the condition that they were suffering from and would share experiences of adapting to living with it. With the reference of these clinician’s, the parents and adolescents were approached. Most of the identified participants

were from rural parts of West Bengal. Hence, the interviews were conducted as per the adolescent’s convenience in their comforting home environment.

In-depth interviews were conducted with the participants with each interview lasting for about 1.5-2 hours. Out of sixteen participants that were selected, nine showed disinterest. They chose to withdraw from the study as most of them were not willing to sign the participant consent form, leaving seven interviewees. The limited number of participants was not of concern as the research uses depth strategies and not sampling strategies that rely on the number of people interviewed. The fact that the participants have experienced the concerned phenomenon being studied was given more importance, rather than adopting a variation sampling method.<sup>27</sup>

### **Explication of the data**

All the interviews were transcribed in full. The first cycle began with coding the excerpts from the data using descriptive codes, and the second cycle was completed by classifying previously generated codes further to add a more analytical structure to the code list.<sup>28</sup> To increase the internal validity of the research, both the authors discussed their readings of the interviews and agreed on generating the categories with each subsequent transcript. Both the authors were not aiming to produce a satisfactory inter-rater reliability score but rather to verify that the analysis presented has been systematically achieved and is supported by data.

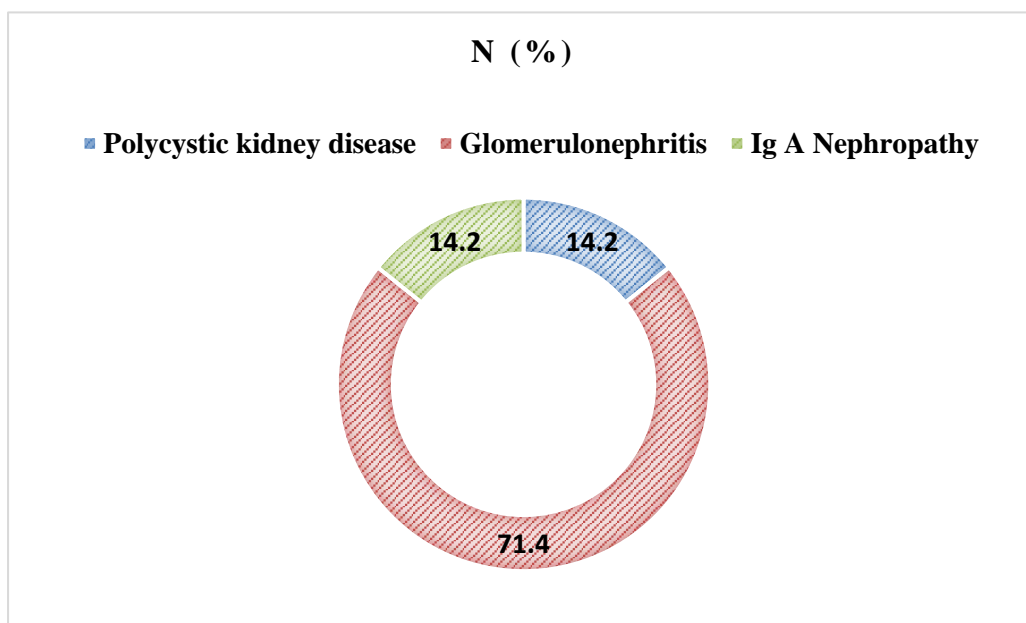
### **Ethical considerations**

The study was approved by the university authority of the Tata Institute of Social Sciences (TISS), Mumbai before the commencement of data collection. The university authority granted permission for data collection against a written agreement that the identities of the participants and the hospitals giving information about the participants would be maintained confidentially by the researchers. Besides, informed consent in written form was taken from each participant before data collection. The ‘informed consent agreement’ form was explained to subjects at the beginning of each interview. The purpose of the research was also mentioned in it and was explained to them. All who ended up being participants agreed with its content and signed.

### **RESULTS**

**Table 1: Sociodemographic characteristics of participants**

		N (%)
Age Category (years)		
10-14		42.8
15-19		57.2
Sex		
Female		71.5
Male		28.5
Education		
Upto 7 <sup>th</sup> class		42.8
Upto secondary school		42.8
Upto higher secondary		14.2
Annual family income		
< 1 lakh		85.7
1-2 lakh		14.3
Religion		
Hindu		57.0
Christian		14.2
Muslim		28.8



**Figure 1: Specific clinical characteristics of Chronic Renal Disease amongst participants.**

The sociodemographic characteristics of the participants are enlisted in Table 1. Most of the participants were females and the annual family income for most of them was below one lakh rupees. Figure 1 shows most of the participants suffered from Glomerulonephritis, a form of CRD.

### **Getting diagnosed with Chronic Renal Disease**

The very first and commonly observed symptom as stated by all the participant adolescents was that of suffering from a ‘swelling’ (oedema) which would not subside. The oedema was present primarily on the face and the feet. This was the onset of CRD, and then they were taken to the doctor by their parents. In other cases, some of the participants also mentioned specifically of noticing frothy urine with brownish discolouration. These self-detected symptoms would usually prompt these individuals to speak to their parents and seek treatment. A participant shared;

*“It all started very suddenly as I was walking home from school and climbing the stairs, I noticed that my leg was swollen and then the next day my full face and eyes were swollen, so initially I thought I was gaining weight. Along with that, I also noticed brown urine with too much froth; I came to know something is not right.”*

Many participants also mentioned of suffering from an unexplained feeling of “feeling sick” or that “something was not right in the body and that could not be described” before the clarity on the diagnosis came through. For example, an adolescent girl said;

*“During that time, I was unable to walk around as I would feel very, very sick and was always lying down in bed. I could not tell as to why I was feeling like that. My body felt swollen all over I was unable to do my regular work like riding my bicycle or even sitting on a bench in my school. I would also need to lie down, and in fact, standing was so difficult, I always would prefer being in bed.”*

Repeated visits to the doctor’s clinics and most often the condition going undiagnosed seemed to create a lot of anxiety, confusion and a stressful situation amongst these adolescents and their families. All the patient’s complaint that the condition would continue

to progress, and there would not be any improvement in their health as arriving at a certain diagnosis took a long time. Finally, after undergoing multiple diagnostic tests and changing a couple of consulting doctors, the condition would get diagnosed.

One of the participant adolescents outlined it very clearly as;

*"I was very anxious because I couldn't understand what was happening to me. One year was gone, and we would go to different doctors, but no one could diagnose the disease."*

The condition going undiagnosed and the increase in symptoms along with the constant feeling of being unwell seemed to cause a lot of stress and irritation among adolescents. A participant explained:

*"Nothing was getting diagnosed, and then the vacations came. I used to play a lot of outdoor games, but this time I was feeling terribly sick and was so disinterested in playing. It all was very disturbing because no one knew what was happening to me".*

Many participants stated that they and their families were unaware of a condition like CRD and trying to understand the nature of the condition further added to their confusion. A participant shared;

*"I have never seen anyone. This was like the very first experience as in my family no one has this. This was a very new thing for my family and me. I couldn't understand what was happening to me."*

### **The restrictive lifestyle and learning to live with CRD**

For all the participants, the dietary restrictions, and the requirement to consume medicines came across as a major interference in their normal lifestyles to the extent that they associated it with causing a lot of mental stress. A participant said;

*"I have to eat diet less in oil and salt always. Also, Coke and such drinks are to be completely avoided. I dislike this the most as others can party and eat all these things. And then it's very irritating taking all the medicines as all this is getting in the way of my normal routine."*

Another said;

*"I have to eat home-made food as my mother puts less salt and oil and makes. I am not supposed to eat such things. I like biryani the most, but because the one bought from outside has a lot more of oil, then she cooks with less oil, especially for me. And I can't be eating chips, and such other fried foods and all of us like that so...it's a loss."*

The medical practitioners advised a major shift towards a more tailored diet that was low in fats, sugars, and salts during the post-diagnosis phase. Also, this was a permanent change in dietary patterns that these adolescents were supposed to incorporate within their lifestyles. Many felt this as a loss of their freedom to eat the foods that they enjoyed eating, whereas their friends and peers could continue with unrestricted diets.

Many participants felt that they had become more dependent on their parents and siblings. Although not for physical activities but in reminding them of taking medicines on time, occasionally coaxing them to consume medicines, especially when there were days when they felt very tired of the medicines. Parents, especially mothers, were more concerned about them consuming a home-cooked diet low on salt and oils and would remind them to refrain from eating foods other than home-cooked. Their inability to enjoy the foods that their peers could enjoy seemed to symbolise the gravity of their condition associated with CRD.

All the participant adolescent's upheld that the treatment regime was very difficult to follow as they were supposed to consume different medicines multiple times in a day while maintaining fixed timings and gaps between each dosage. The medications required them to take food before consuming their pills. An adolescent said in angst;

*“I hate taking the medications, but then the whole day I have to take medicine at least 8-9 times. I have to wake up, and then there is one medicine, and then I have to compulsorily eat something even when I am not hungry and then it’s time for the next medicine so this goes all day long and I am constantly worrying about taking medicines. Then there is a tonic and more medicine which makes my mouth very bitter, so I mix it with the rice and somehow swallow it during the dinner.”*

Participants were required to take medicines during school hours too. It was however noted that the ones who were on a diuretic drug (causing increased passing of urine) would completely avoid taking the drug during school hours and sometimes even post the school timings. The main reason being that this drug would cause frequent urination. Regarding self-management, participants reported more difficulties in keeping to their medications than to their diet appropriately. Some of the participants feared that consuming medicines in front of their peers would draw judgements about their medical conditions. However, some of the participants were happy to share their condition with their peers and considered peer support as instrumental in bettering their lives. A participant mentioned;

*“I avoid taking that (diuretic) medicine on school days as I feel like passing urine every 7-10 minutes. I know that I need to take all medicines then I take it after school hours, but sometimes I never take it as I forget and then it is time for going for tuition classes. I hate it when I have to take permission many times to go to the toilet. In the class, everyone keeps asking about the sickness and then I don’t like to speak about it as they will keep on talking.”*

Participants shared their perceptions of the condition affecting their academic performance and staying in pace with it, which they now find difficult. They believed this condition adversely impacted their schooling due to drastic reductions in energy levels. While the early schooling seemed well-managed the later years of schooling, post the diagnosis of their condition seemed disrupted.

An adolescent girl explained;

*“I am tired of the disease and eating too many medicines. I was very good at football and other sports. I would defeat even the boys, but after this (illness) my energy levels completely dipped. I can no longer play like that, and the entire stamina is lost. But I also know that I must take all medicines otherwise anything can go wrong anytime...but in so many medicines, I always forget so many times. But then my friends are aware of this, and then they constantly remind me that I will recover and do well.”* Whereas another participant shared;

*“I was a bright student. But after the disease, there were so many things like going to the doctor all the time, missing school because I was swelling like a balloon. After school, I used to go to play and then the tuitions, but now, I cannot play as there is no energy left for attending tuition classes then. After coming at (sic) home, in the night also I used to study, but now after dinner, I just sleep off...it’s like there is no energy left.”*

Adolescent female participants also mentioned of body image issues as a side-effect of consuming the medicines. Excessive weight gain and hair loss seemed to be common challenges due to the side-effects of CRD medication. This was predominantly felt by the adolescent females who seemed frustrated and had started despising the medication. For example;

*“I was always very thin. I gained almost twelve kilos in the past year because of this treatment.”*

Another girl said;

*“I had long and beautiful hair. Because of this medicine, my hair started falling out just too much. I had to cut them off. I have also gained weight, and I hate these changes. It gives me a very negative feeling”.*

However, it must be noted that most of the participants reported that to maintain a worthwhile quality of life, they were trying hard to consume the medication on time. Whenever problems with medication were discussed, they were mostly concerning remembering to take tablets regularly as many different medicines were to be consumed every day and the feeling of loss of energy levels that was associated with the condition. Many of the participants stated that they had become inattentive in the class post developing this condition. They attributed this to the treatment regime because of which they felt fatigued and tired continuously. They were able to distinguish between being physically tired due to strenuous work and feeling tired all the while due to dip in energy levels. The negative body image perception seemed to compromise the self-confidence of these participant girls.

There seemed to be a wider impact on the financial condition of the family. In several cases, the participants mentioned that their parents had to borrow money to bear the cost of medicine and other diagnostic's and treatment associated with their condition. This subjected the participants and their family members to go through a lot of financial hardships. Many participants mentioned that their parents and other family members were making ends meet as they had to pay towards the medical expenses of the participants. One of the participants stated that as his father was daily wage labour, and they did not have much savings, his father had mortgaged their house to get money to pay towards the medical expenses. Incidences of borrowing money from the relatives and moneylenders for paying the medical expenses of their children were quite common. For example, a participant shared;  
*"The treatment costs a lot, and I don't know how my parents will manage. They avoid speaking in front of me, but I know."*

**Table 2: Segregated themes from responses of the participants about getting diagnosed and living with CRD**

Main Themes	Sub themes
Getting diagnosed with CRD	<ul style="list-style-type: none"> <li>- Commonly observed symptoms</li> <li>- Anxiety, confusion related to the condition</li> <li>- Inability to understand prognosis of the disease</li> </ul>
Restrictive Lifestyle	<ul style="list-style-type: none"> <li>- Food restrictions</li> <li>- Medication</li> <li>- Inability to participate adequately in schooling and sports activities</li> </ul>
Learning to live with the condition	<ul style="list-style-type: none"> <li>- Complying with the changed food and medication requirements (positive stance)</li> <li>- Abomination towards compromised physical activities and self-confidence (negative stance)</li> </ul>

## DISCUSSION

### **Going beyond charting responses- Seeking adolescent's perspectives about living with CRD**

Despite certain shortcomings, this research has addressed a significant gap in research knowledge concerning the lives of adolescent's living with CRD, namely by directing the research towards asking and engaging these young people directly about what life is like for them.

In the case of the adolescent participants, it seems a difficult choice that they make of having to choose a restrictive lifestyle to improve the disease prognosis. At the same time, learn to live with the daunting challenges that it presents. It must be noted that the process of diagnosis seemed to be similar in most of the cases wherein most of the cases were initially misdiagnosed. This is a matter of concern as the only way to prevent CRDs from progressing to ESRD is early detection and reliance on trained medical personnel along with institutional measures to slow down its progression.<sup>29</sup> The diagnosis of CRD came across as an ambiguous process for the participants and their parents, who seemed uncertain about what might be wrong with them. Following the diagnosis, the parents and the participating adolescents could not understand the prognosis of the condition. They seemed to be adjusting to the condition, especially while making sense of how to accommodate the condition in their lives. The demand for a sudden change in their lives marked by a constant feeling of being unwell and suffering from marked physical symptoms and the relative ambiguity surrounding them seemed to make the participant adolescents feel anxious and stressed about their medical condition. This kind of anxieties, panic when unable to understand the disease is commonly seen in studies about chronic diseases<sup>30</sup> (Table 2).

CRD is a chronic condition that confines the lives of these adolescents by demanding a major shift to more prescribed and restrictive lifestyle. Most of the participants considered the dietary changes as major concerns wherein the food that was cherished and considered as normal in their age group could no longer be a part of their new dietary regime. The findings are consistent with the other research studies, in this area wherein they reported in their research, children participants with ESRD perceived the dietary changes and restrictions as extremely demanding and felt frustrated while adhering to such changes.<sup>30,31</sup>

Of substantial concern for most of the participants were the rigour of treatment and its interference with daily schooling activities. The demands of taking timely medication and that too, which came in with considerable side-effects was seemingly frustrating. Along with the medication, they experienced a feeling of being depleted of their bodily energies while simultaneously suffering from trying to establish a pattern of living with demands for care management with restricted activities as many of them could no longer play physically demanding sports. On a similar note, a study in India involving children with nephrotic syndrome has also shown lower school performance of these children compared to a control group.<sup>32</sup> A few other researchers too, have noted difficulties with schooling in children and young people with CRD.<sup>33</sup> Researchers have noted that adolescents with chronic condition perceive more negative body image as compared to the ones who do not suffer from any such condition.<sup>34</sup> Weight gain and hair loss because of CRD and the ongoing doses of medicine led to body image issues among the female adolescent participants who portrayed a dismal outlook of living with such a condition. A study about the perception of adolescent living with end-stage renal disease states showed that developmentally adolescence is the time when teens are forming their identity and self-image. It is then that body image issues do affect

them socially, physically, and psychologically.<sup>11</sup> The lives of the adolescent participants conveyed a paradoxical nature in terms of suffering; struggling to cope with the stringent lifestyle changes and yet trying to adapting to the disease to moving forward in life.

## Conclusion

Unfortunately, CRD is underdiagnosed and hence an undertreated condition, which leads to lost opportunities for prevention of complications and worst outcomes for patients. An improved awareness amongst medical professionals by adequate training in diagnosing nephrological conditions would help in early diagnosis. It is established that if we diagnose CRD early, its progression to ESRD can be retarded significantly, quality of life can be improved, and, once the patient reaches ESRD, its outcome of therapy is better. Upon recognising the symptoms, patients can be directed for screening for CRD. These involve cheap but effective methods like testing spot sample of urine for hematuria and or proteinuria (both conditions are suggestive of renal insufficiency). It is important to check if the utilisation of simplistic and cheap measures like urine dipstick test could essentially help improve detection of the disease in a low resource setting like India. Many renal and urinary tract disorders may be asymptomatic for a long period. Such routine urine screening programs, especially at the school level, are recommended as a fundamental step in early identification of renal damage.

## DECLARATIONS

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