

**Appendix III: Questionnaire**

**EXPERIENCES OF CAREGIVERS AND CARE NEEDS OF CHILDREN WITH CONGENITAL HEART DISEASE AT KENYATTA NATIONAL HOSPITAL**

Questionnaire

**Section A: Caregiver characteristics**

- 1. Gender  
Male [ ] Female [ ]
- 2. Age (in years): .....
- 3. Residence

Urban [ ] Rural [ ]

- 4. Educational level

No formal education [ ] Primary level [ ] Secondary level [ ] Tertiary level [ ]

- 5. Employment status

Employed [ ] Unemployed [ ]

- 6. Average monthly income? (Ksh).....

- 7. Parity: .....

- 8. Number of ANC visits?.....

- 9. Presence of comorbidity

Yes [ ] No [ ]

- 10. If yes, which one?.....

- 11. Place of Delivery: .....

- 12. KNH [ ]

- 13. Home [ ]

- 14. Other health facility [ ]

- 15. Mode of Delivery:

Spontaneous Vertex Delivery [ ] Breech vaginal [ ]

Cesarean Section [ ]

**Section B: Patient's data:**

- 16. Sex:

Male [ ] Female [ ]

17. Birth order .....
18. Age at diagnosis of CHD (years).....
19. Symptoms experienced prior to diagnosis  
 Fast breathing [ ] Cough [ ] Fever [ ] Fatigue [ ] Rapid heartbeat [ ]  
 Fainting [ ] Bluish color [ ]
20. Were you referred out of KNH?  
 Yes [ ] No [ ]
21. What treatment modality was adopted?  
 Medication [ ] Catheter procedures [ ] surgery [ ] Heart transplant [ ]
22. What is the type of congenital heart disease?  
 Atrial Septal Defect [ ] Atrioventricular Septal Defect [ ]  
 Coarctation of the Aorta [ ] Double-outlet Right Ventricle [ ]  
 Others (specify).....

**Section C: Healthcare needs of children**

23. Does the child have insurance?  
 Yes [ ] No [ ]
24. Have you received any support from the government or any organization?  
 Yes [ ] No [ ]  
 24a. If yes, which organization?.....
25. Is your child enrolled in any social protection program?  
 Yes [ ] No [ ]
26. If yes, Which one?.....
27. Is your child attending school?  
 Yes [ ] No [ ]
28. If no, why?  
 Too weak to go through education system [ ]  
 Lack of enough finances to allow schooling [ ]  
 I am afraid to take him to school [ ]  
 Others (specify)
29. Does your child perform physical activities?  
 29a. if yes, how many hours per day?.....
30. Was your child admitted in the first one year after birth?  
 Yes [ ] No [ ]

## **Appendix VI: Focus group discussion guide**

1. Do you know the medical condition your child is having?
2. When did you know that your child had a medical problem?
3. How did you feel?
4. What was your reaction after your doctor told you that your child has congenital heart disease?
5. Did you receive any counselling from hospital professional?
6. How would you describe your journey so far?
7. Have you been receiving enough support from?
  - i. Spouse
  - ii. Family
  - iii. Friends
  - iv. Government
  - v. Healthcare providers
8. Do you think your child will lead a normal life?
9. What are the major challenges that you have been facing in your journey raising a child with this medical condition?
10. What do you do to cope with challenges of raising a child with congenital heart disease?