

# Factors influencing retinoblastoma patients/siblings compliance with clinic appointments

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## ABSTRACT

**Objectives:** To investigate the compliance and non-compliance of retinoblastoma patients/siblings with their appointments at the Retinoblastoma Clinic in the Pediatric Division of a tertiary eye care center, and to evaluate the contributing factors.

**Methods:** This descriptive type of case series was conducted between May 1999 and May 2002 at the Retinoblastoma Clinic of King Khaled Eye Specialist Hospital, Riyadh, Kingdom of Saudi Arabia. Retinoblastoma patients/siblings were surveyed when they attended the clinics. Each family was interviewed with the help of a close-ended questionnaire. The sample of patients and their siblings were selected based on inclusion and exclusion criteria, and their charts were reviewed.

**Results:** The study included 260 retinoblastoma patients and their siblings, 134 (51.5%) were males, and 126 (48.5%) were females. One hundred and forty-seven (56.5%) of the retinoblastoma patients/siblings in the sample were scheduled for follow up. One hundred and sixty-eight (64.6%) of retinoblastoma families were contacted by phone and reminded of their children's appointments, 37 (14.2%) were not contacted, and for 55

(21.2%) of the sample subjects, it was not known whether contact was made or even attempted. The compliance rate was 86.2%. One hundred and ninety-five (95.1%) of non-contacted patients/siblings' families attended subsequently. One hundred and thirty-six (52.3%) felt they faced barriers to treatment. Sixty-eight (26.2%) completed treatment, and 175 (67.3%) were still being followed up in the Retinoblastoma Clinic. Six factors were found to influence compliance with clinic appointments: type of appointment, frequency of no shows per clinic, frequency of no shows per patient/sibling, number of non-contacted patients/siblings, telephone contact, and patients with no contact details.

**Conclusion:** There was a high compliance rate among those scheduled for check up or follow-up. Family education and continuous updating of patients' phone contact numbers can overcome non-compliance and maximize the benefits of the phone call mechanism. Factors affecting compliance found in this study should be used for improving the compliance rate.

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Genetic studies<sup>1,2</sup> have shown that the incidence of retinoblastoma (Rb) has increased from 2.9-5 per 100,000 in last decade. For early detection, timely treatment of Rb and tumor recurrences, and avoidance of the development of new cases among offspring and siblings is essential. It is vital that Rb patients/siblings

comply with clinic appointments and the treatment protocol. The Pediatric Division at the King Khaled Eye Specialist Hospital (KKESH) in Riyadh has been conducting a twice-monthly Retinoblastoma Clinic for long-term genetic counseling of Rb patients/siblings and their families. Patients/siblings' families are

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reminded by telephone of their children's appointments before the clinic date. This study investigated the attitude of Rb patients/siblings in complying with the clinic/treatment schedule, determined influencing factors, and evaluated the remainder of the system in order to improve the compliance rate.

**Methods.** In this prospective study, Rb patients/siblings attending the Retinoblastoma Clinic at King KKESH, between May 1999 and May 2002 were surveyed. The sample of Rb patients/siblings were selected based on inclusion/exclusion criteria. This included Rb patients/siblings being present at the follow up clinic for a one year minimum, siblings' being followed up until the age of 30 months, consent of Rb patients/siblings' families to be interviewed in the clinic, and exclusion of all Rb patients/siblings deceased or referred to other institutions. In addition, children who presented after birth with a family history were considered to have received prenatal and postnatal counseling. Those who presented during the first year after birth without a family history were assumed to have had postnatal counseling only. Others had late presentation counseling. The questionnaire comprised demographic details such as age, literacy, area of residence, education, and financial status of the family. Satisfaction regarding management and services offered was also evaluated. The questions related to the barriers for compliance included fear of attending the clinic. Selected Rb patients/siblings' charts were also reviewed. All possible errors related to data, and non-responses were taken into account. After the data were collected, the results were tabulated and analyzed using SPSS-Frequencies, cross tables' chi-square test, and bi-variate correlations statistics.

**Results.** The sample size under study was 260 patients/siblings. Two hundred and eighteen (83.8%) were Saudis, and 42 (16.2%) were of other different nationalities. One hundred and thirty-four (51.5%) were males and 126 (48.5%) were females. **Table 1** shows the mean and the range for a number of patients, clinics, and factors of compliance/non compliance. **Table 2** presents results pertaining to family history, consanguinity, treatment plan acceptance, type of appointment, phone contact, compliance, barriers to treatment, and its completion. Six factors were found to influence compliance with clinic appointments: type of appointment, frequency of no shows per clinic, frequency of no shows per patient/sibling, number of non-contacted patients/siblings, telephone contact, and patients with no contact details (**Figure 1**). While 195 (95.1%) of the Rb patients/siblings' families who were not contacted by phone prior to the scheduled clinic turned up, 10 (4.9%) did not show

**Table 1** - Details of patients, clinics and factors of non-compliance.

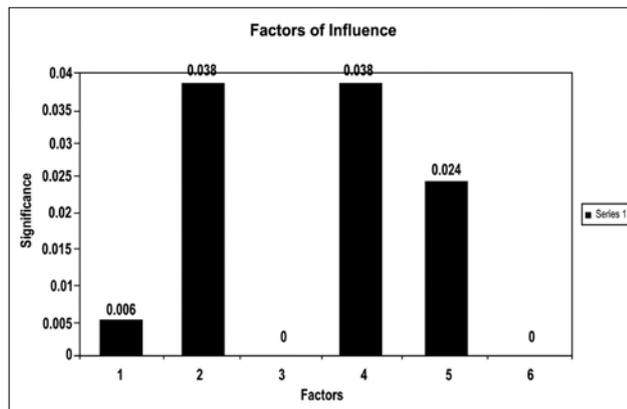
| Variable  | Mean | Range         |
|---|------|---------------|
| <b>Age at Presentation (months)</b>               |      |               |
| Unilateral Retinoblastoma                         | 31.9 | 288.00 - 0.43 |
| Bilateral Retinoblastoma                          | 17.3 | 144.00 - 0.50 |
| Rb siblings                                       | 10.6 | 84.00 - 0.20  |
| Clinic (patients) size                            | 30.8 | 40.0 - 12.0   |
| Number of non-contacted Patients/sibling families | 5.25 | 11.0 - 0.00   |
| Wrong telephone number                            | 1.9  | 7 - 0.00      |
| Frequency of no shows per clinic                  | 7    | 15.0 - 2.0    |
| Frequency of no shows per patient/sibling         | 1.4  | 11.0 - 0.00   |

**Table 2** - Results of compliance/non-compliance factors and patients survey.

| Factors                                  | n   | (%)    |
|--|-----|--------|
| <b>Family history</b>                    |     |        |
| Positive                                 | 103 | (39.6) |
| Negative                                 | 157 | (60.4) |
| <b>Type of appointment</b>               |     |        |
| Follow up                                | 147 | (56.5) |
| Examination under sedation               | 81  | (31.2) |
| Examination under anesthesia             | 21  | (8.1)  |
| Check-up                                 | 11  | (4.2)  |
| <b>Treatment plan</b>                    |     |        |
| Yes                                      | 237 | (91.1) |
| Yes but dropped out within normal limits | 8   | (8.3)  |
| No                                       | 2   | (0.8)  |
| Refused at first but came back           | 12  | (4.6)  |
| Rejected radio/chemotherapy              | 1   | (0.4)  |
| <b>Contact</b>                           |     |        |
| Contacted                                | 168 | (64.6) |
| Uncontacted                              | 37  | (14.2) |
| Unknown                                  | 55  | (21.2) |
| <b>More factors</b>                      |     |        |
| <b>Consanguinity</b>                     |     |        |
| Related                                  | 120 | (46.1) |
| Not related                              | 140 | (53.9) |
| <b>Compliance</b>                        |     |        |
| Comply                                   | 224 | (86.2) |
| Not comply                               | 36  | (13.8) |
| <b>Obstacles/barriers</b>                |     |        |
| Yes                                      | 136 | (52.3) |
| No                                       | 124 | (47.7) |
| <b>Treatment completion</b>              |     |        |
| Yes                                      | 68  | (26.2) |
| Dropped out within normal limits         | 11  | (4.2)  |
| Deceased                                 | 6   | (2.3)  |
| Under treatment and follow-up            | 175 | (67.3) |

**Table 3** - Leading obstacles/barriers to compliance with retinoblastoma clinic appointments.

| Obstacles/barriers  | Response % |
|---|------------|
| Financial/travel costs  | 32.7       |
| Transportation related problems: Fear of driving cars/riding trains/flying on planes/car breakdowns-road accidents  | 36.2       |
| Phobias/fears of physicians/nurses/new discoveries/lengthy treatment including examination under anesthesia, examination under sedation procedures/examination room instruments | 13.4       |
| Guardian availability/permission from employer  | 33.5       |
| School/examination interruptions  | 15.4       |
| Waiting too long in the outpatient clinic   | 3.1        |



**Figure 1** - Statistically significant factors influencing compliance/non-compliance with retinoblastoma clinic appointments: 1 - Type of appointment; 2 - Frequency of no shows per clinic; 3 - Frequency of no shows per patient/sibling; 4 - Number of uncontacted families prior to clinics dates in the study; 5 - Telephone contact of families prior to retinoblastoma clinics; 6 - No contact of families/non-compliance with retinoblastoma clinics (factors and significance  $p$ -value represent X-axis and Y-axis).

up as scheduled. There were no significant statistical differences for variables such as age at presentation, diagnosis, treatment, complications, satisfaction with child health in pre-, intra-, and post-treatment phases, and obstacles/barriers to treatment with compliance/non-compliance with retinoblastoma clinic appointments. **Table 3** shows the barriers to treatment based on our survey. Pearson's correlations of many of the variables studied were found to be highly significant; **Table 4** demonstrates the relevant variables' correlations.

**Discussion.** Our study showed that there was a positive correlation between the variables of age at presentation and treatment up to date interval ( $p=0.026$ ) (**Table 4**). Unilateral and bilateral Rbs presented to the Retinoblastoma Clinic at different mean ages (**Table 1**). Regardless of family history and genetic relationship (**Table 2**), the emphasis is on the

importance of early detection and compliance with Rb treatment and clinic appointments. This is true despite our study finding that diagnosis was not a significant predictor of compliance to Rb clinics ( $p>0.05$ ). The earlier the detection, the shorter the treatment interval. Correlations of the variables shown in **Table 4** were significant at 0.01 and 0.05. Also, the Chi Square Test from cross tables demonstrated significant statistical differences between compliance/non-compliance and the variables: type of appointment, number of non-contacted Rb families, frequency of no shows per clinic, frequency of no shows per patient /sibling, telephone contact, and no contact no show (**Figure 1**). With reference to the clinic size, it was noted that the larger the clinic size (Rb patients/siblings), the greater the number of non-contacted Rb patients/siblings families, the higher the frequency of no show per clinic. The frequency of no show per clinic was also directly related to frequency of no shows per patient/sibling. The number of non-contacted families was proportional to the number of unaffected siblings of Rb patients. Group tests gave significant differences between laterality groups (unilateral and bilateral Rb patients, and siblings of Rb patients) in their attitudes about pre-treatment counseling and patients/siblings health post-initial treatment. Further, group testing demonstrated that the 3 groups were different in the age at presentation (unilateral and bilateral  $p=0.004$ , and unilateral and siblings  $p=0.000$ ), the number of non-contacted families (unilateral and bilateral  $p=0.022$ ), and the number of affected siblings (unilateral and bilateral  $p=0.014$ ). For comparison to other clinical settings, Rajaram<sup>3</sup> addressed the role of illness explanatory models in non-compliance of some cancer patients to follow-up treatment. Mazur and Merz<sup>4</sup> found that approximately 50% of severe pneumonia male patients accepted life sustaining long-term treatment even though it resulted in persistent cognitive disability. Our study showed that there were no significant statistical

**Table 4** - Correlations between variables relating to compliance/non compliance with clinic appointments

| Variable                                       | Age at presentation |         | Clinic size (Scheduled patients per clinic) |         | Frequency of no shows per clinic |         | Number of uncontacted patient/sibling families |         | Wrong telephone number |         | Discharge interval |         |
|--|---------------------|---------|---|---------|----------------------------------|---------|--|---------|------------------------|---------|--------------------|---------|
|  | ±R                  | p value | ±R  | p value | ±R                               | p value | ±R   | p value | ±R                     | p value | ±R                 | p value |
| Number of uncontacted patient/sibling families |                     |         | +0.427                                      | 0.00    |                                  |         |  |         |                        |         |                    |         |
| Wrong telephone number                         |                     |         | +0.424                                      | 0.00    |                                  |         | + 0.572  | 0.000   |                        |         |                    |         |
| Frequency of no Shows per clinic               |                     |         | +0.315                                      | 0.00    |                                  |         | + 0.400  | 0.000   | +0.307                 | 0.00    |                    |         |
| Frequency of no shows per patient/sibling      |                     |         |   |         | +0.172                           | 0.014   |  |         |                        |         | +0.258             | 0.031   |
| Number of unaffected siblings                  |                     |         |   |         |                                  |         | + 0.170  | 0.015   |                        |         |                    |         |
| Treatment up-to-date interval                  | +0.138              | 0.026   |   |         |                                  |         | +0.280   | 0.000   |                        |         |                    |         |
| R = Pearson correlation; P = Probability value |                     |         |   |         |                                  |         |  |         |                        |         |                    |         |

differences between prenatal/postnatal counseling, and the tendency to comply with clinic appointments or the completion of treatment ( $p>0.05$ ). At KKESH, counseling of families is still conducted primarily by the attending physician. All patients received counseling, but the benefit of such counseling depended on the family history, prenatal, postnatal, and late presentation. In the sample, 33 (30.6%) received early prenatal counseling, 21 (19.4%) were counseled post-natally, and 54 (50.0%) received late presentation counseling. However, the cross-tables Chi Square test demonstrated that mother's education was significant in postnatal counseling ( $p=0.014$ ). Our results also indicated that the number of non-contacted families correlated significantly with the number of unaffected siblings. It was also shown that all the counseling was conducted directly in person. Non-direct counseling such as using the phone or mail, or both, was absent and its value consequently was lost. The program at KKESH used the families with single/multiple affected members' technique, whereby Rb siblings were followed up to the age of 30 months. This can be confirmed by applying the Hetero-duplex technique. In a study,<sup>5</sup> such a genetic technique identified a newborn as normal using gene diagnosis. In the 15-month follow-up visit, the initial prediction of "normal" and that the child inherited

the band pattern of his mother, not the mutant Rb allele from his bilateral Rb father, was confirmed. Our study has shown significant association of compliance with appointment and type of appointment ( $p=0.00$ ). Patient/sibling non-compliance gave significantly negative correlation with the dosage of external beam therapy ( $p=0.042$ ), but positive correlation with adjuvant chemotherapy ( $p=0.012$ ). The number of non-contacted families was found to be directly related to the total number of examinations under anesthesia (EUA) and examinations under sedation (EUS) procedures that were undergone by Rb patients/siblings, but inversely related to the total number of external beam therapy doses administered to Rb patients. However, with 26.2% of our sample having completed treatment, the variables compliance, and treatment completion gave no significant statistical differences ( $p=0.525$ ). The relationship between patients' perceptions of overmedication, drug compliance, and side effects, was investigated in a study by Fincke et al<sup>6</sup> in 1986. It was found that patient perception of overmedication correlated with decreased drug compliance and negative side effects. Our study showed that 91.5% of the sample population was satisfied with the pre-treatment plan, and 8.5% was not. However, at the end of one year of management, there was 91.9%

satisfaction, and the unsatisfied with pre-treatment plan, fell to 8.1%. We concluded that there was no association of level of satisfaction with compliance. The study found that the variables satisfaction with the pre-treatment counseling, intra-treatment side effects, and child health post-initial treatment were not significant statistical predictors of treatment completion ( $p>0.05$ ). Gardner et al<sup>7</sup> found that most patients who were reluctant to be hospitalized changed their minds after discharge. An investigation<sup>8</sup> using a behavior model found that there was a relationship between patient belief and behavior. Rajaram, in a case study in 1998,<sup>3</sup> found that the completion rate was up to 30%, and concluded that it was important that patients/siblings complete their treatment program and its associated protocols from time of diagnosis until medical discharge to avoid increased cervical cancer morbidity and mortality rate. Of our sample, 26.2% completed treatment and were discharged, 4.2% dropped out within normal limits, 2.3% were deceased, and 67.3% were still receiving treatment or continuing to be followed up in the clinic. A study<sup>9</sup> using the Health Belief model to investigate the difference between completers and dropouts from 2 HIV intervention trials for 2 groups of volunteers, revealed that better methods are needed to attract and maintain participation levels. Similarly, factors revealed in our study affecting compliance need to be explored further to improve the compliance rate. Even though compliance and diagnosis showed no significant statistical difference, it was observed that the frequency of no shows per patient/sibling and discharge interval correlated ( $p=0.031$ ), and the number of non-contacted families correlated with treatment up-to-date interval with a  $p=0.000$ . Metastasis and optic nerve, choroidal, scleral invasion, extra-ocular involvement, or second non-ocular tumor, or both showed no significant correlation or statistical differences with compliance with appointments ( $p>0.05$ ). This finding of our investigation is in agreement with the outcome of a study by Kopelman et al,<sup>10</sup> which found that neither optic nerve, choroidal nor scleral invasion was a significant predictor of death. Fiscella<sup>11</sup> found that skepticism about medical care may serve as a risk factor for early death. Our study showed that post-natal counseling is significantly influenced by mother's education ( $p=0.014$ ). This has a major impact on morbidity and survival of the disease. The findings of a study by Nelson et al in 1999,<sup>12</sup> demonstrated the importance of continuous monitoring of the cost of medical care. The disadvantaged always perceived cost as a major hurdle to receiving necessary health care. Low socio-

economic factors such as lack of health insurance, low education, low income and unemployment needed to be improved in order to minimize premature mortality and morbidity.

Cross-Tables' Chi Square Test gave no statistical differences that were significant for compliance and obstacles/barriers ( $p>0.05$ ). Treatment completion and barriers also showed no significant difference ( $p=0.145$ ). Our study showed that the type of appointments significantly predicted compliance/non compliance, with a  $p$ -value of 0.006. Our survey showed that half the sample population is of low income, and that the vast majority of parents received no higher than secondary school education. Our survey also showed that 32.7% encountered financial barriers to compliance with appointments, 36.2% faced transportation difficulties, 13.4% have phobias, 33.5% expressed concerns regarding guardian availability, 15.4% felt that school attendance was a barrier to compliance, and 3.1% reported that waiting too long for service was a barrier to compliance with treatment (**Table 3**). This might explain the reasons behind Saudi Arabia's Ministry of Health policies to pay patients' bills for travel and treatment costs, together with housing and pocket spending money if necessary during hospitalization for treatment, and always guarantee clinic appointments at KKESH, which facilitate the reach out program to Rb patients/siblings. For comparison, Roberts et al<sup>13</sup> investigated barriers associated with late prenatal care initiation in a middle to upper class Midwestern community in the USA. They found that 12% (98) of the 813 women studied faced barriers to receiving prenatal care. Of the middle class women surveyed, 49% had difficulties getting appointments, 26.5% faced problems with finding childcare, and 14.3% of these women lacked transportation.

In conclusion, 6 factors were found to influence Rb patients/siblings compliance with clinics appointments. Those were type of appointment, frequency of no shows per clinic, frequency of no shows per patient/sibling, number of non-contacted patients/siblings, telephone contact, and patients with no contact details. Other factors which were not found to be significant included age at presentation, diagnosis, treatment, complications, satisfaction with child health in pre-, intra-, and post-treatment phases, together with barriers to treatment. The non-compliance rate was 13.8%. Correlations amongst many of the variables studied were highly significant. Finally, it is important to emphasize family education and continuous updating of patients' phone contact numbers in order to overcome non-compliance and maximize the benefits of the phone call mechanism.

We propose that further research of the influencing factors found in this study and the variables' correlation relationships needs to be conducted

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