Acceptability of prenatal testing and termination of pregnancy in Pakistan

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Abstract This study aimed to assess acceptability of prenatal testing (PNT) and termination of pregnancy (TOP) for a range of conditions in Pakistani parents with and without a child with a genetic condition. A structured questionnaire assessing acceptability of PNT and TOP for 30 conditions was completed by 400 Pakistani participants: 200 parents with a child with a genetic condition (100 fathers and 100 mothers) and 200 parents without an affected child (100 fathers and 100 mothers). There was a high level of interest in PNT, where over 80 % of parents in all four study groups would want PNT for the majority of the conditions. There was comparatively less interest in TOP for the same conditions (ranging from 5 to 70 % of parents, with mothers of an affected child being most interested). Parents were most likely to be interested in TOP for conditions at the serious end of the continuum. More than half of the participants in each group would consider TOP for anencephaly and quadriplegia. The interest in PNT and TOP for a range of conditions suggests that rapidly developing PNT technologies are likely to be acceptable in Pakistan, a low-middle income level and Muslim country. The comparatively lower level of interest in TOP for the same conditions highlights ethical dilemmas that such technologies are likely to raise.

Keywords Prenatal testing · Termination · Mothers · Fathers · Pakistan

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Introduction

Prenatal testing for foetal anomalies is an integral part of antenatal care in many countries (EUROCAT Central Registry 2010) and usually involves a first-trimester risk assessment for the common aneuploidies and a second-trimester foetal ultrasound scan to identify foetal anomalies. Women identified at high risk of having a foetal anomaly are then offered prenatal diagnosis, involving invasive procedures such as amniocentesis or chorionic villus sampling (de Jong et al. 2011). In the case of a diagnosed foetal anomaly, parents may be offered a termination of pregnancy.

Advances in genetic technology can allow cheap and rapid carrier testing for various recessive conditions, particularly for families with affected children (Carr et al. 2011). In addition, the discovery of fragments of cell-free foetal DNA that circulate in maternal blood has led to the development of non-invasive prenatal testing (NIPT) involving a simple blood test (Lo et al. 1997; Chiu et al. 2011) and a focus on developing NIPT for various chromosomal, monogenic and sex-specific conditions (Chitty et al. 2012; Hill et al. 2012; Twiss et al. 2013). Such advances will soon make it possible to expand the offer of prenatal testing (PNT) and subsequent termination of pregnancy (TOP) for affected foetuses for a larger range of conditions in many countries, including middle-low income countries. The successful implementation of such technology in clinical practice is partly dependent upon the acceptability of PNT and TOP for various conditions in target populations.

PNT is available in Pakistan as chorionic villus sampling in a number of major cities, including Lahore, Rawalpindi, Faisalabad, Multan, Hyderabad and Karachi, for conditions such as thalassaemia, trisomies 21, 18 and 13 and Duchenne muscular dystrophy (DMD). For some conditions, such as microcephaly and fragile X, PNT is made available to parents in Pakistan by transporting samples to laboratories in other countries. Termination of pregnancy is also available in

Pakistan for affected fetuses following PNT. Although Pakistan's law only permits TOP if the mother's life is at risk (Arif et al. 2008), PNT is provided by health professionals using a fatwa (religious ruling issued by Islamic scholars) (Jafri et al. 2012).

PNT and TOP have been available in Pakistan for almost two decades. However, there is little published research on the acceptability of PNT and TOP in Pakistan for a range of conditions, although there is some research on specific conditions. For example, research shows that PNT and TOP are acceptable in Pakistan for beta-thalassaemia major particularly when individuals are provided with a religious decree suggesting that TOP is permissible for the condition (Ahmed et al. 2000). PNT and TOP are also acceptable in Pakistan for Down syndrome, mainly due to the social stigma experienced by parents (Ahmed et al. 2013). These studies also suggest that parents negotiate their religious beliefs alongside personal experiences and consider pragmatic concerns about the impact of having a child with a condition (Ahmed et al. 2000, 2013). They also suggest that the acceptability of PNT and TOP may vary depending on whether individuals already have a child with a genetic condition (Ahmed et al. 2012; Sawyer et al. 2006). However, these studies have been conducted with parents of affected children, and there is little research on the acceptability of PNT and TOP for these or any other conditions in parents with no affected children.

Studies conducted in Muslim populations in the UK and Saudi Arabia for a range conditions, both with parents with and without a child with a genetic condition, show that acceptability of PNT and TOP varies for different conditions (Alsulaiman and Hewison 2007; Ahmed et al. 2012; Hewison et al. 2007) and is mainly influenced by perceptions of the quality of life of a child with the condition, including the extent to which the child would be 'suffering' (Ahmed et al. 2008). Studies conducted in non-Muslim populations in Western countries show similar findings (Green et al. 2004).

Such research suggests that people are likely to have different levels of acceptability for PNT and TOP for different conditions in countries with different cultures, resources, and health and social care facilities for affected children. Research also suggests that parents of affected children are more likely to be interested in PNT and TOP than parents with no affected children because of their experiences (Ahmed et al. 2012; Atkin and Ahmad 2000; Sawyer et al. 2006). Given the advances in genetic testing technology and the increasing availability of testing opportunities for families with no affected children (Chitty et al. 2012; Twiss et al. 2013), it is important to explore attitudes to PNT and TOP of both parents with and without a child with a genetic condition.

In Pakistan, there is no state social support system and there are poor health care facilities for individuals with disabilities (Karim et al. 2004; Rathore et al. 2011). Therefore, a child with a disability is likely to remain dependent on family

members for health and social care, and caring for such a child could be considered a lifelong commitment (Ahmed 1995; Rahman and Obaid-ur-Rahman 2005). These factors may influence parents' acceptability of PNT and TOP for various conditions, and studies in Muslim populations in the UK and Saudi Arabia may not be relevant to a low-resourced country like Pakistan. Therefore, this study aimed to assess acceptability of PNT and TOP for a range of conditions in a Pakistani population. The study also aimed to explore any differences in acceptability between parents who already had a child with a genetic condition and those who did not.

Method

Questionnaire

A self-completion, structured questionnaire developed by Hewison et al. (2007) and available in Urdu was adapted for this study. The questionnaire contained brief descriptions of 30 conditions ranging in severity and functional impairment (intellectual, psychological, sensory and physical). This questionnaire was chosen because it included such a range of conditions and was likely to enable exploration of participants' thresholds for PNT and TOP. Descriptions were used instead of names of the conditions to minimise the influence of pre-existing perceptions associated with certain diagnoses and also because some names were not literally translatable or may be unfamiliar to participants. Participants were asked to respond to two questions for each of the conditions described: whether or not they would want a prenatal test and whether or not they would terminate an affected pregnancy. For each of the two questions, participants could respond 'yes', 'no' or 'not sure' (the questionnaire is described in and appended to Hewison et al. (2007)). For the purpose of the questionnaire, participants were asked to assume a hypothetical scenario in which testing would be conducted early in pregnancy, would not carry any risk to the mother or baby, would be conducted using routinely collected blood and would provide a diagnostic result.

Participants and recruitment procedure

The study was approved by the appropriate ethics committee within the Pakistan Medical Association, Lahore. Data was collected between January 2009 and December 2010. A total of 400 parents were recruited for the study, including 200 parents (100 fathers and 100 mothers) with an affected child (including beta-thalassaemia major, deafness, blindness and learning difficulties) via service providers in four different health and educational institutions, and 200 parents (100 fathers and 100 mothers) without an affected child via designated nurses at a public hospital and a private health clinic.

Individuals agreeing to participate in the study were introduced to a researcher (the first author, male), who administered all the questionnaires face-to-face. A female research assistant was present during data collection with the mothers to enable them to feel comfortable and to openly express their views. All participants completed the questionnaire independently and separately from their partners. Not all participants were couples. Recruitment of participants continued until there were 100 participants in each group. The authors do not have access to the number of potential participants who declined to participate when they were approached by service providers or nurses.

Results

Data were managed in SPSS version 16. Data analysis included descriptive statistics, Cochran's Q tests to compare difference between proportions for related samples and non-parametric Mann-Whitney U tests for unrelated samples because the distribution of scores was non-normal.

Sample characteristics

All the participants were Pakistani and described their religion as Islam. Table 1 presents demographic data of the four study groups.

Mann-Whitney U test showed a significant effect of group for education and income, where the parents with an affected child had significantly less income ($P<0.001$) and were less educated ($P<0.001$) than the parents without an affected child (see Table 1).

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For brevity, the names of conditions will be used from here on instead of the descriptions of the conditions.

Figures 1 and 2 show the percentage of mothers and fathers with and without affected children answering 'yes' to the questions about PNT and TOP, respectively. In both figures, the conditions are rank ordered according to the percentage of the total sample who responded 'yes' to the PNT question.

Figure 1 shows parents' high level of acceptability of PNT for all the conditions, where the majority of participants in all four study groups would want PNT for all or nearly all the conditions with the exception of 'not preferred gender' in which 61 % of parents would want PNT.

Cochran's Q tests for differences between correlated proportions for participants saying 'yes' to PNT for each condition show that potential acceptability of PNT for different conditions varied significantly within each of the four subgroups ($P<0.001$).

Table 1 Demographic characteristics of participants ($n=400$)

		All Fathers				All Mothers			
		With affected children ($n=100$)	With unaffected children ($n=100$)	Mann-Whitney U test (P value)		With affected children ($n=100$)	With unaffected children ($n=100$)	Mann-Whitney U test (P value)	
Age in years	Mean (SD)	36.8 (5.4)	34.3 (5.1)	<0.001		33.9 (5.7)	31.5 (5.1)	0.003	
Total number of children	Median (range)	4 (1–8)	2.5 (1–10)	<0.001		3 (1–8)	3 (1–7)	0.002	
Number of affected children	One child	77	–			82	–		
	More than one child	16	–			18	–		
Monthly family income in Pakistani rupees	Mean (SD)	11,170 (7,888.8)	33,565 (32,466.4)	<0.001		10,878 (10,401)	32,850 (34,563)	<0.001	
Education ^a	Median (range)	4 (1–7)	6 (1–7)	<0.001		3 (1–7)	5 (1–7)	<0.001	

^a 1=illiterate, 2=primary education (up to class 5), 3=secondary education (up to class 8), 4=matric (UK equivalent to GCSE), 5=FA (UK equivalent to A levels), 6=undergraduate degree, 6=master's degree, 7=higher than master's degree

Fig. 1 Participants who said 'yes' to PNT in each group and in the full sample. Conditions are ordered by the percentage of people saying 'yes' to PNT in the full sample

Figure 2 shows that parents from all four subgroups were most likely to accept TOP for the same conditions (anencephaly, quadriplegia, trisomy 13 or 18, severe learning disabilities and DMD). From observation of Fig. 2, parents with an affected child, particularly mothers, were more accepting TOP for most of the conditions than parents without an affected child. A variable level of acceptability in TOP was observed in 26 of the conditions, ranging between 25 and 80 %. For the remaining four conditions (not preferred gender, coronary, mild LDMH and cleft lip and palate), the level of interest was below 25 %. There was no condition for which all the parents would decline TOP.

Cochran's Q tests confirm that participants within the four subgroups had significantly different levels of acceptability of TOP for the different conditions ($P < 0.001$ in each case).

Individual participants' acceptability of prenatal testing and termination of pregnancy for the 30 conditions

To summarise interest across conditions, participants' no, not sure and yes responses to the two questions for the 30 conditions were scored as 0, 1 and 2, respectively. By adding these scores, a total score was calculated for each participant for

PNT and for TOP, where a total score of 0 showed that participants were not interested in PNT or TOP for any of the conditions, and a total score of 60 showed that they were interested in PNT (Cronbach's $\alpha = 0.98$) or TOP (Cronbach's $\alpha = 0.96$) for all the conditions.

Eighty-three percent of the mothers and 85 % of the fathers with an affected child and 76 % of the mothers and 74 % of the fathers without an affected child scored 58/60 to 60/60 and so were interested in PNT for all or most of the conditions. Conversely, 1 % of the mothers and 2 % of the fathers with an affected child and 3 % of the mothers and 6 % of the fathers without an affected child scored zero, i.e. they were not interested in PNT for any of the 30 conditions. Median total scores for the four groups ranged between 58 and 60, showing that they had similar levels of interest in PNT. Mann-Whitney U tests show that there were no significant differences between the median scores of the four groups for PNT, except for mothers with an affected child who would consider PNT for significantly more conditions than the fathers without an affected child ($P < 0.05$).

For TOP, there was much variability in the number of condition for which parents in each of the four subgroups would consider TOP. Overall, 7 % of mothers and 14 % of

Fig. 2 Participants who said ‘yes’ to TOP for each condition and ‘yes’ to PNT in the full sample. Conditions are ordered by the percentage of people saying ‘yes’ to PNT in the full sample

fathers with an affected child and 13 % of mothers and 21 % of fathers without an affected child would not consider TOP for any of the 30 conditions. Median total scores for TOP for the four groups ranged from 13.5 to 34, indicating differences in the level of interest in TOP between them. Mann-Whitney *U* tests showed that mothers with an affected child had significantly more favourable attitudes to TOP and fathers without an affected child had significantly less favourable attitudes to TOP than those of the other subgroups ($P > 0.05$).

Effect of income and education on acceptability of prenatal testing and termination of pregnancy for the 30 conditions

To explore the effect of income on the acceptability of PNT and TOP, the monthly income in Pakistani rupees (Rs) for the four

study groups was divided into two subgroups to represent parents with ‘low’ and ‘high’ income—up to and including Rs 20,000 and above Rs 20,000, respectively. Table 2 shows that the majority of the parents with an affected child had a low income, while the proportion of parents without an affected child was similar in the low- and high-income subgroups. Mann-Whitney *U* tests show that there was no significant difference in median scores for PNT between the parents in the low- and high-income groups. Parents within both the low- and high-income subgroups had a high level of interest in PNT.

Mann-Whitney *U* tests also show that there was no significant difference in median scores for TOP between the parents in the low- and high-income groups (see Table 3). Parents within both the low- and high-income subgroups had a similar level of interest in TOP.

Table 2 Monthly income and parents’ median scores for PNT

	Fathers with affected child	Mothers with affected child	Fathers without affected child	Mothers without affected child
Low income (up to and including Rs 20,000)	<i>N</i> =90 <i>M</i> =58	<i>N</i> =94 <i>M</i> =60	<i>N</i> =48 <i>M</i> =58	<i>N</i> =50 <i>M</i> =60
High income (above Rs 20,000)	<i>N</i> =10 <i>M</i> =58	<i>N</i> =6 <i>M</i> =60	<i>N</i> =52 <i>M</i> =58	<i>N</i> =50 <i>M</i> =60
Mann-Whitney <i>P</i> value	0.727	0.993	0.200	0.532

N number of cases, *M* median score for PNT (range 0–60)

Table 3 Monthly income and parents' median scores for TOP

	Fathers with affected child	Mothers with affected child	Fathers without affected child	Mothers without affected child
Low income (up to and including Rs 20,000)	<i>N</i> =90 <i>M</i> =25	<i>N</i> =94 <i>M</i> =34.50	<i>N</i> =48 <i>M</i> =9	<i>N</i> =50 <i>M</i> =23
High income (above Rs 20,000)	<i>N</i> =10 <i>M</i> =27.50	<i>N</i> =6 <i>M</i> =14	<i>N</i> =52 <i>M</i> =16	<i>N</i> =50 <i>M</i> =27.5
Mann-Whitney <i>P</i> value	0.796	0.115	0.089	0.309

N number of cases, *M* median score for TOP (range 0–60)

To explore the effect of education on the acceptability of PNT and TOP, the four study groups were divided into two subgroups to represent parents with low and high education—up to and including matric level (equivalent to the UK General Certificate of Secondary Education (GCSE) level, the standard school exits academic qualification at age 16) and above matric level, respectively. Mann-Whitney *U* tests showed that there was no significant difference in median scores for PNT between the parents in the low- and high-education groups (see Table 4).

Mann-Whitney *U* tests also showed that there was no significant difference in median scores for TOP between the parents in the low- and high-education groups, except for the mothers with an affected child (see Table 5). Mothers with an affected child and low education had a higher median score for TOP than mothers with an affected child and high education ($P<0.05$).

Discussion

Similar to other studies (Ahmed et al. 2012; Alsulaiman and Hewison 2007; Hewison et al. 2007), our findings show that the majority of parents had a high level of potential interest in PNT for a range of conditions. Most of the parents, but not all, from all of the subgroups would opt for PNT for all or most of the conditions. The high level of potential interest in PNT for a range of conditions may have been because of the key aspects of PNT that participants were asked to consider, including the elimination of the risk of miscarriage (Babay 2004), the early

timing of the test (Modell et al. 2000) and its description as a diagnostic test. Another reason may be that parents had not understood or considered the implications of receiving a positive test results, including the possibility of having to make a difficult decision about TOP at a later stage and whether it was worth having PNT if the only subsequent options for an affected foetus were continuation or TOP. These findings highlight the need for patient information to enable pregnant couples to make informed decisions about PNT.

Our findings show that parents were comparatively less interested in TOP for the same conditions. This finding may have been due to the general belief that TOP is not permitted in Islam (Ahmed et al. 2006; Jafri et al. 2012). Nevertheless, parents were interested in TOP for a range of conditions, particularly those that could be perceived as severe, such as, quadriplegia, anencephaly, thalassaemia, severe learning disabilities/mental handicap, trisomy 13 or 18 and Turner syndrome. Even parents who rejected TOP for most conditions would accept TOP for one or more of these conditions. Our findings also show a higher level of variation in the number of conditions for which parents would opt for TOP compared to PNT, further suggesting that parents' acceptability may have been based on their perceptions of individual conditions. This interest in TOP for a range of conditions suggests that assumptions should be avoided about the role of religion in decision-making about TOP and the conditions for which parents would or would not have TOP.

The overall interest in TOP for a range of conditions, albeit to different degrees, is surprising in a Muslim country. A fatwa on TOP is currently available in Pakistan, but it places responsibility on health care professionals to determine the severity

Table 4 Education and parents' median scores for PNT

	Fathers with affected child	Mothers with affected child	Fathers without affected child	Mothers without affected child
Low education	<i>N</i> =74 <i>M</i> =58	<i>N</i> =73 <i>M</i> =60	<i>N</i> =31 <i>M</i> =60	<i>N</i> =47 <i>M</i> =60
High education	<i>N</i> =26 <i>M</i> =58	<i>N</i> =27 <i>M</i> =60	<i>N</i> =69 <i>M</i> =58	<i>N</i> =53 <i>M</i> =60
Mann-Whitney <i>P</i> value	0.641	0.673	0.697	0.385

N number of cases, *M* median score for PNT (range 0–60)

Table 5 Education and parents' median scores for TOP

	Fathers with an affected child	Mothers with an affected child	Fathers without an affected child	Mothers without an affected child
Low educated	<i>N</i> =74 <i>M</i> =26	<i>N</i> =73 <i>M</i> =40	<i>N</i> =31 <i>M</i> =10	<i>N</i> =47 <i>M</i> =26
High education	<i>N</i> =26 <i>M</i> =23	<i>N</i> =27 <i>M</i> =26	<i>N</i> =69 <i>M</i> =14	<i>N</i> =53 <i>M</i> =22
Mann-Whitney <i>P</i> value	0.565	0.011	0.618	0.838

N number of cases, *M* median score for TOP (range 0–60)

of the conditions for which TOP should be allowed (Jafri et al. 2012). The acceptability of TOP for a range of conditions in our study highlights the need for debate at policy level to inform and develop law governing PNT services in Pakistan and the need for medical education on this topic. Furthermore, research is needed on health care professionals' perceptions of their role in delivering PNT services in Pakistan given the responsibility placed on them to determine the severity of tested for conditions.

The difference in interest in PNT compared to TOP suggests that potential users may opt for testing for most conditions for information only about the foetus. Similar to other studies, people may value PNT because of its practical and psychological benefits in preparing for the birth of an affected child, such as having a plan in place for delivery, delivery in a specialist centre, having time to come to terms with the diagnosis and time to learn about the condition (Lewis et al. 2013). The difference in interest in PNT compared to TOP could also be due to participants' poor understanding of the purpose of PNT. We acknowledge that attitudes may be a poorer guide to behaviour and that what people say they would do may be different to what they would actually do in the real situation (La Piere 1934). Nevertheless, our findings suggest that service providers should not make assumptions about what individuals would do with information following PNT or that acceptability of testing means acceptability of TOP.

In many Western countries, the aim of PNT programmes is to enable parents to make informed reproductive choices. However, there is little evidence in Pakistan that existing availability of PNT services is to inform reproductive choices in a similar way. Developers of any future PNT programme in Pakistan or similar developing countries would need to give careful consideration to the number and type of conditions for which PNT is offered and clarify the aims of such testing from a service provision perspective in relation to enabling parents to make informed reproductive choices.

There was a high level of interest in PNT in all the subgroups but particularly in the mothers with an affected child. Similarly, mothers of an affected child were most interested in TOP. These findings may be due to mothers in Pakistan having the main responsibility for childcare (Yousafzai et al.

2011). However, research on British Pakistanis shows a higher level of acceptability of PNT and TOP in fathers of children with a condition than that in mothers (Ahmed et al. 2012). This difference between fathers in the UK and Pakistan could be partially explained by UK research with British Pakistani fathers, which shows that there is a continuing trend towards fathers being involved in a broader range of childcare responsibilities and that mothers' and fathers' roles are less strictly differentiated than they used to be (Hauari and Hollingworth 2009). Nevertheless, further research is needed to explain differences in fathers' attitudes towards PNT and TOP between these countries.

Group comparisons also showed that parents of affected children would be more likely to have TOP than parents without affected children. These findings suggest that they may be more appreciative of the realities of caring for an affected child (Yousafzai et al. 2011; Ahmed et al. 2013), through experiences of both clinical and social implications of various condition (Croot et al. 2008; Ahmed et al. 2013). For example, research in Pakistan shows that parents of children with learning difficulties such as Down syndrome have inadequate social support services and, therefore, are wholly responsible for caring for their child with the condition, which can lead to financial, social and psychological implications for the parents (Ahmed et al. 2012; Arif et al. 2008). The increased amount of out of pocket expenses for care and increased demand of care can also result in less time available for employment (Van Riper 2007), further increasing financial constraints on parents with children with a condition.

Currently in Pakistan, prenatal services are mostly provided by the private sector or through NGOs and are available in a few large cities. Parents have to travel long distances, and the majority of them either have to fully or partially pay for these services, whereas only a small number of people receive these services free of charge. Pakistanis have a low per capita income of Rs 133,712 (US\$1,372) (Ministry of Finance 2011), and research in Pakistan has shown that cost of testing is an important factor in the uptake of prenatal service (Baig et al. 2006; Naseem et al. 2008). Advanced genetic technology in the future is only likely to be available for a selected number of people who can afford it and may increase already existing inequalities in prenatal health care in the country.

Nevertheless, our findings provide an insight into potential service users' perspectives that can help inform policy and practice for PNT services in Pakistan and similar developing countries.

The demographic findings showed that parents of unaffected children had significantly higher income and were more educated and that parents with an affected child were significantly older and had more children. These differences may be due to the recruitment strategy employed in the study. For example, parents of an affected child were recruited from charity and publicly funded health and educational organisation. There were no privately funded similar organisations from which a more affluent group of parents with affected children could be recruited. Therefore, most of the parents of an affected child belonged to the low-income and low-education category. A more diverse sample of parents with no affected children in terms of income was included in the study by recruiting from both publicly and privately funded clinics. Nevertheless, the difference in the organisations from which the parents were recruited seems to have led to an overall significant difference in income. Similarly, differences in education could be explained by the relationship between low income and lower educational attainment (Douglas-Hall and Chau 2007). These demographic differences are unlikely to have biased the results given that there was no statistical difference in the comparisons of median scores for PND and TOP between low and high income.

Conclusion

Overall, the interest in PNT and TOP for a range of conditions suggests that rapidly developing PNT technologies are likely to be acceptable in Pakistan, a low-middle income level and Muslim country. The comparatively lower level of interest in TOP for the same conditions highlights ethical dilemmas that such technologies are likely to raise. Our findings highlight the need for better education for both health professionals likely to offer PNT services and potential users and the need for research to explore potential service users' reasons for their level of interest in PNT and TOP.

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Conflict of interest Hussain Jafri, Jenny Hewison, Eamonn Sheridan and Shenaz Ahmed declare that they have no conflict of interest.

Compliance with ethics guidelines All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (Research Ethics Committee, Pakistan Medical Association, Lahore) and with the Helsinki Declaration of 1975, as

revised in 2000 (5). Informed consent was obtained from all patients for being included in the study.

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