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Knowledge of Down's syndrome Screening amongst Patients and Health Care Professionals in Sri Lanka

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Abstract

Aim: Different screening strategies have been proposed to detect high risk women during pregnancy for Down syndrome. In order to achieve effective screening, the patient making the choice and the staff offering the test must have a reasonable understanding of all facts relevant to the test. The aim of this study was to assess the existing knowledge and awareness of antenatal Down syndrome screening in patients and obstetric stakeholders across eight major obstetric centres in Sri Lanka.

Methods: This was a prospective study carried out between January and June 2013 in eight tertiary care settings in 7 districts representing Northern, Western, Eastern, Southern and central provinces in Sri Lanka. A validated questionnaire was translated from English into Singhalese and Tamil and independently translated back to English and piloted to confirm the accuracy of the translation. This translated questionnaire was distributed among antenatal patients and obstetric unit staff members.

Results: A total of 1116 patients and 535 staff members were recruited. Present overall knowledge of Down syndrome among antenatal patients was poor in all 7 districts. Majority of patients were not aware that available options of screening for Down syndrome (Awareness about nuchal translucency-21.6% (95% CI 14.7-30.6%), biochemical screening-26.3% (95% CI 18.7-35.7%) invasive procedures-23.3 (95% CI, 16.1-32.5%). Majority of staff members were also not aware about available screening strategies (Awareness about nuchal translucency-29.3% (95% CI 21.3-38.9%), biochemical screening-26.9% (95% CI 19.2-36.3%) but their knowledge of diagnostic tests were high (invasive procedures- 59.4% (49.6-68.5%). Moreover, there is no difference in knowledge in different part of the island.

Conclusions: Adequate education on available screening methods of Down syndrome for the staff is a timely need so that the means would be available to disseminate knowledge to the wider patient and public populations.

Keywords: Knowledge; Down syndrome; Combined screening; Antenatal; Sri Lanka

Introduction

Sri Lanka has been highly regarded as an international success story of how to deliver maternity care on a developing world budget [1,2]. This success is demonstrated by maternal mortality rates closer to some developed countries than those of its South Asian neighbours [3]. Although Sri Lanka is making good progress on the World Health Organization (WHO) millennium developmental goals in maternal morbidity and mortality [4,5], first trimester assessment in pregnancy dating, chorionicity and Trisomy 21 screening has not yet been incorporated into the routine antenatal care model [6,7]. Downs syndrome is caused by chromosomal aneuploidy and is the most common cause of intellectual disability globally. It is characterized by distinctive phenotype traits and multiple systemic complications with around 44% of those born being diagnosed with congenital heart defects [8]. Routine screening for trisomy 21 has been incorporated in to antenatal care in a few countries [9]. Definitions of screening tests have been refined over the years from Wilson and Jungner in 1968 to the WHOs criteria today [10]. There are a number of criteria to consider when recommending a screening test; it should be simple, practical to implement and feasible in the public sector. Combination of maternal age, a nuchal translucency (NT) scan and a biochemical test for pregnancy-associated plasma protein-A and serum-free beta-human chorionic gonadotropin (combined test) is considered the standard for Down's syndrome screening [9]. Other standards are used elsewhere and in some places novel methods of screening such as none invasive prenatal testing (NIPT) using fetal cell free DNA in maternal serum has been introduced recently with promising success [11,12].

As levels of education have increased along with access to information, obstetricians have found more women requesting screening for Downs's syndrome. There have been many definitions of screening over the years. One criterion regularly specified is that the program should ensure informed choice [13]. In order for informed choice to be possible the patient making the choice must have a reasonable understanding of all facts relevant to the test. For this reason when considering the implementation of a screening test in a population, it is important to understand the baseline knowledge of that population. In addition it is also important to understand the current knowledge of staff that would be involved with the undertaking of such a screening test. There is no robust data in Asian region specifically looked at Knowledge of combined screening among both pregnant women and staff. The aim of this study was to assess the existing knowledge and awareness of first trimester combined Trisomy 21 screening in patients and obstetric stakeholders across eight major Obstetric centres in Sri Lanka.

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Methods

This was a descriptive study carried out in antenatal clinics across eight major hospitals in Sri Lanka between March and August 2013. A self-administered questionnaire was used to assess the knowledge of pregnant women and Obstetric staff members in first-trimester combined Trisomy 21 screening and the associated issue of pregnancy termination. In order to identify the key areas of knowledge and to maintain uniformity for comparison, a questionnaire used in previous study was employed [14]. The questionnaire was translated from English into Singhalese and Tamil and re-translated back to English to confirm the accuracy of the translation. Furthermore, the questionnaire was pre-tested on a cohort of 50 patients and staff members in one study site followed by direct interviews to identify any ambiguities arising in questions due to the translation process, thus maximising the validity.

The eight centres were Mahamodara Teaching Hospital, De Soysa Hospital for Women, Castle Street Hospital for Women, Jaffna Teaching Hospital, Batticaloa Teaching Hospital, Puttlam Base Hospital, Peradeniya Teaching Hospital and Ampara District General Hospital. All hospitals included in the study are government funded and represent antenatal women and obstetric staff from a cross-section of Sri Lankan society. Obstetric staff included was different grades of doctors, midwives and nurses. At each hospital a consultant was identified who then nominated a junior doctor to work with the recruited patients and staff members. Staff and patients were given time to read the questionnaire and then asked by the junior doctor if they had any questions or wanted any clarification. They then completed the questionnaire themselves. This process was conducted to ensure participants had given their informed consent. For the purpose of analysis staff were divided by profession, into three groups; Nurses, Midwives and Doctors. For all knowledge based questions, the proportion of respondents who selected the correct answer was calculated with 95% CI. A cut off of 90% correct answers for each question was chosen to define adequate knowledge for both patients and staff members [14]. Ethics clearance for this study was obtained from District General Hospital Ampara ethics review board.

Results

A total of 1116 antenatal patients and 410 obstetric staff members were included. Socio-demographic characteristics of the study population are given in Tables 1 and 2. The majority of patients have an education up to ordinary level at school and most of the staff members have worked for more than one year. Patients and staff members are almost equally recruited from 8 centres. The proportion of patients and staff members who had selected the correct answer for the ten questions on Down's syndrome screening is given in Tables 3 and 4 respectively. A majority of patients were not aware the optimum time of dating/nuchal translucency (NT) scan (21.9% 95%, CI 19.2% to 24.2%), association of increased NT with DS (21.5% 95%, CI 19.1 to 24.1), combined screening for DS (23.5% 95%, CI 21.3 to 26.4) and confirmatory tests of DS (23.5% 95%, CI 21.3 to 26.4). Comparatively, staff member knowledge of trisomy 21 screening is better than patients but it is still below the expectations (optimum time of dating/nuchal translucency (NT) scan (58.0% 95%, CI 53.1% to 63%), association of increased NT with DS (35.1% 95%, CI 30.6 %to 39.9%), combined screening for DS (48.0% 95%, CI 43.2% to 52.9%) and confirmatory tests of DS (70.2% 95%, CI 65.7% to 74.5%). The majority of patients were not aware of the legal status for termination of pregnancy in fetuses with lethal anomalies or with an anomaly which could cause severe neuro-development handicap. However, a significant proportion of patients approved of termination of pregnancy in such fetal anomaly (Table 5). Most of the staff members were aware of the legal status yet approved the termination of pregnancy in cases of severe fetal anomaly (Table 6).

	N (%)
Hospital	
• Ampara District General Hospital	88 (7.8)
• Castle Street Hospital for Women	134 (12)
• De Soysa Hospital for Women	123 (11)
• Jaffna Teaching Hospital	152 (13.6)
• Mahamodara Teaching Hospital	167 (15.2)
• Peradeniya Teaching Hospital	145 (12.9)
• Puttlam Base Hospital	231 (20.7)
• Batticaloa Teaching Hospital	76 (6.8)
Age	
• 15-24	335 (30)
• 25-34	648 (58.1)
• ≥ 35	133 (11.9)
Marital Status	
• Married	1105 (99.0)
• Unmarried	11 (1)
Level of Education	
• 1-No Education	6 (0.5)
• 2-Primary up to Grade 5	25 (2.3)
• 3-Secondary up to O Level	624 (55.9)
• 4-A-Level or vocational training	223 (19.9)
• 5-Tertiary/ postgraduate	40 (3.6)
• 6-Education status unknown	198 (17.8)
Parity	
• Primi	407(36.5)
• Multi	709 (63.5)

Table 1: Socio-demographic and obstetric characteristics of patients sample.

	N (%)
Hospital	
• Ampara District General Hospital	70 (17.1)
• Castle Street Hospital for Women	72 (17.6)
• De Soysa Hospital for Women	75 (18.3)
• Jaffna Teaching Hospital	31 (7.5)
• Mahamodara Teaching Hospital	42 (10.2)
• Peradeniya Teaching Hospital	32 (7.5)
• Puttlam Base Hospital	68 (16.6)
• Batticaloa Teaching Hospital	20 (5.2)
Age	
• 15-24	7 (1.7)
• 25-34	210 (51.2)
• 35-44	102 (24.9)
• 45-54	67 (16.3)
• ≥ 55	24 (5.9)
Occupation	
• Nurse	186 (45.4)
• Midwife	138 (33.7)
• Doctor	86 (20.9)
Work Experience	
• <1 year	45 (10.9)
• 1-10 years	190 (46.8)
• 11-20 years	95 (23.2)
• 21-30 years	67 (16.3)
• ≥ 31 years	13 (2.8)

Table 2: Socio-demographic and obstetric characteristics of staff sample.

Discussion

Our results showed that knowledge of first trimester combined Down's syndrome screening amongst both patients and staff in Sri Lanka is poor. The challenge of building up a foundation of knowledge in this area, such that patients would be empowered to make an informed choice were screening to be offered, is a considerable task. This could take place in a number of settings, including antenatal clinics and public health campaigns. As a foundation, concept of antenatal screening and strategies should be incorporated in to respective curricula of medical students, nurses and midwifes. Subsequently,

	Overall Answer Correct (Total-1116) % (95% CI)	Answer Correct in Education Group 1 (Total- 6) % (95% CI)	Answer Correct in Education Group 2 (Total- 25) % (95% CI)	Answer Correct in Education Group 3 (Total- 624) % (95% CI)	Answer Correct in Education Group 4 (Total- 223) % (95% CI)	Answer Correct in Education Group 5 (Total- 40) % (95% CI)	Answer Correct in Education Group 6 (Total- 198) % (95% CI)
Time of Dating/NT Scan	21.9 (19.2 to 24.2)	0 (0.0 to 39.0)	16 (6.4 to 34.6)	24.7 (22.1 to 28.2)	34.4 (28.1 to 40.1)	22.5 (12.1 to 36.1)	0.5 (0.09 to 2.8)
Increased NT indicates higher risk	21.5 (19.1 to 24.1)	0 (0.0 to 39.0)	32 (17.2 to 51.6)	24.2 (21.7 to 27.9)	29.8 (24.1 to 35.2)	32.5 (20.1 to 47.7)	1.0 (0.28 to 3.6)
Can blood tests be used in DS screening?	26.3 (24.2 to 29.3)	33.3 (9.7 to 70.0)	36 (20.3 to 55.5)	31.9 (28.2 to 36.2)	27.8 (22.1 to 34.1)	37.5 (23.7 to 52.8)	3.0 (1.4 to 6.5)
Identify risk factor for DS	15.6 (13.1 to 18.2)	16.7 (3.0 to 56.3)	16 (6.4 to 34.6)	18.4 (15.8 to 21.8)	21.1 (16.2 to 27.3)	12.5 (5.5 to 26.1)	0.5 (0.09 to 2.8)
Are Blood tests and NT used to screen DS?	23.5 (21.3 to 26.4)	16.7 (3.0 to 56.3)	32 (17.2 to 51.6)	26.7 (23.3 to 30.1)	33.2 (27.1 to 40.2)	22.5 (12.1 to 36.1)	1.5 (0.52 to 4.4)
Can CVS/Amniocentesis confirm DS?	23.3 (21.3 to 26.4)	16.7 (3.0 to 56.3)	36 (20.3 to 55.5)	26.3 (23.1 to 29.9)	34.1 (28.1 to 40.9)	20.0 (10.2 to 35.1)	1.0 (0.28 to 3.6)
Is there Procedure related miscarriage with above invasive testing?	18.7 (17.1 to 21.2)	0 (0.0 to 39.0)	22.8 (14.3 to 47.6)	27.5 (20.1 o 26.2)	22.3 (17.1 to 27.1)	27.5 (16.3 to 42.8)	0.5 (0.09 to 2.8)
Is DS associated with malformations such as heart defects?	39.2 (36.2 to 42.3)	16.7 (3.0 to 56.3)	20 (8.9 to 39.1)	45.4 (41.2 to 49.4)	55.2 (49.1 to 62.2)	60.0 (44.6 to 73.6)	1.0 (0.28 to 3.6)
Can Fetal malformations be diagnosed by scans?	60.1 (57.1 to 63.1)	33.3 (9.7 to 70.0)	48 (30.0 to 66.5)	71.0 (67.2 to 74.1)	78.6 (72.1 to 83.1)	92.5 (80.1 to 97.4)	1.5 (0.52 to 4.4)
What is the suitable time for a scan to diagnose fetal malformations?	25.1 (23.2 to 28.3)	33.3 (9.7 to 70.0)	12 (4.2 to 29.9)	29.8 (26.2 to 34.2)	34.5 (29.2 to 41.3)	22.5 (12.1 to 36.1)	1.5 (0.52 to 4.4)

Table 3: Questionnaire responses from patient sample(CI-Confidence interval) 1-No Education, 2-Primary up to Grade 5, 3-Secondary up to O Level, 4-A-Level or vocational training, 5-Tertiary/ postgraduate, 6-Education status unknown (NT-Nuchal translucency, DS-Down's syndrome CVS-chorionic villus sampling).

	Overall answer Correct (Total- 410) % (95% CI)	Answer Correct in Nursing Group (Total- 186) % (95% CI)	Answer Correct in Midwifery Group (Total- 138) % (95% CI)	Answer Correct in Doctor Group (Total- 86) % (95% CI)
Time of Dating/NT Scan	58 (53.0 to 63.0)	49.4 (42.4 to 56.6)	68.1 (59.9 to 75.3)	60.4 (49.9 to 70.1)
Increased NT indicates higher risk	35.1 (30.6 to 39.9)	30.6 (24.5 to 37.6)	37.6 (30.0 to 46.0)	40.6 (30.9 to 51.3)
Can blood tests be used in DS screening?	32.1 (27.9 to 36.9)	27.9 (22.0 to 34.8)	26.8 (20.1 to 34.8)	50.0 (39.7 to 60.3)
Identify risk factor for DS	57.8 (52.9 to 62.5)	47.3 (40.3 to 54.5)	45.6 (37.6 to 53.9)	68.6 (58.2 to 77.4)
Are Blood tests and NT used to screen DS?	48.0 (43.2 to 52.9)	42.4 (35.6 to 49.7)	52.1 (43.9 to 60.3)	53.4 (43.0 to 63.7)
Can CVS/Amniocentesis confirm DS?	70.2 (65.7 to 74.5)	63.9 (56.9 to 70.5)	65.2 (56.9 to 72.7)	91.8 (84.1 to 96.0)
Is there Procedure related miscarriage with above invasive testing?	47.3 (42.5 to 52.0)	38.1 (31.5 to 45.3)	34.7 (27.4 to 43.0)	87.2 (78.5 to 92.7)
Is DS associated with malformations such as heart defects?	93.9 (91.1 to 95.8)	96.2 (92.4 to 98.2)	88.4 (82.0 to 92.70	97.6 (91.9 to 99.4)
Can Fetal malformations be diagnosed by scans?	96.8 (94.7 to 98.1)	97.3 (93.9 to 98.9)	95.6 (90.8 to 97.9)	97.6 (91.9 to 99.4)
What is the suitable time for a scan to diagnose fetal malformations?	77.5 (73.3-81.3)	72 (65.2 to 78.0)	77.5 (69.9 to 83.7)	89.5 (81.3 to 94.4)

Table 4: Questionnaire responses from staff sample (CI-Confidence interval) (NT-Nuchal translucency, DS-Down's syndrome, CVS-chorionic villus sampling).

regular teaching and training programs should be implemented at regional level for all obstetric stake holders. Once obstetric staffs are adequately educated, patient awareness programs would need to be commenced in pre-conception and early antenatal clinics. This would eventually disseminate knowledge to the patients.

Any screening strategy within the public sector must be cost effective, easy to deliver and achieve the agreed targets. Serum screening for Down's syndrome is costly therefore it may not be pragmatic in public sector at the movement. Of all available screening tests for Down's syndrome, an ultrasound based screening strategy would be most practical and cost effective in Sri Lankan at present as almost all the obstetric units in the public sector are equipped with ultrasound scanning machines. However, the main challenge is to train doctors to perform first trimester ultrasonography and fetal nuchal translucency [15]. Moreover, audit and monitoring of the screening system is essential in improving the quality of screening and ensure women receive the best available risk evaluation. It is recommended therefore that nuchal translucency measurement should have an external quality assessment and assurance schemes. Systematic training of obstetric ultrasound skills has recently been started in Sri Lanka [15].

Knowledge in both Down's syndrome and screening methods for Down's syndrome is diverse worldwide. A recent south Asian study, Baxi et al. studied the awareness of triple test screening for Down's syndrome in Indian women [16]. Of the 745 women included in that study, only 14% were aware about triple test [16]. Authors have concluded that there is lack of awareness regarding Down's syndrome

	Overall Yes (Total-1116) % (95% CI)	Yes in Education Group-1 (Total-6) % (95% CI)	Yes in Education Group 2 (Total-25) % (95% CI)	Yes in Education Group 3 (Total-624) % (95% CI)	Yes in Education Group 4 (Total-223) % (95% CI)	Yes in Education Group 5 (Total-40) % (95% CI)	Yes in Education Group 6 (Total-198) % (95% CI)
Is Medical abortion legal in foetuses with lethal malformations or ending up severe neuro-development disability in Sri Lanka?	27.2 (25.0 to 30.0)	16.7 (3.0 to 56.0)	16 (6.1 to 35.2)	32.9 (29.3 to 37.4)	34.5 (29.3 to 41.2)	35 (22.2 to 50.1)	1.5 (0.52 to 4.2)
Do you approve of Medical abortion in fetuses with lethal malformations?	41.3 (38.2 to 44.1)	33.3 (9.7 to 70)	32 (17.2 to 52.2)	45.0 (41.2 to 49.1)	61.9 (55.1 to 68.3)	67.5 (52.2 to 80.2)	0.7 (0.28 to 3.6)

Table 5: Questionnaire responses from patient sample to opinion on legality of abortion (CI-Confidence interval) 1-No Education, 2-Primary up to Grade 5, 3-Secondary up to O Level, 4-A-Level or vocational training, 5-Tertiary/ postgraduate, 6-Education status unknown.

	Overall (Total- 410) % (95% CI)	Yes in Nursing Group (Total-186) % (95% CI)	Yes in Midwifery Group (Total-138) % (95% CI)	Yes in Doctor Group (Total-86) % (95% CI)
Is Medical abortion legal in foetuses with lethal malformations or ending up severe neuro-development disability in Sri Lanka?	74.1 (70.2 to 78.2)	71.5 (65.2 to 78.2)	66.7 (58.4 to 74.3)	91.9 (84.1 to 96.1)
Do you approve of Medical abortion in foetuses with lethal malformations?	86.1 (82.1 to 89.2)	88.2 (83.1 to 92.1)	88.4 (82.1 to 93.2)	77.9 (68.2 to 85.2)

Table 6: Questionnaire responses from staff sample to opinion on legality of abortion (CI-Confidence interval).

screening among general population in India especially regarding various methods and their availability y and they have suggested a systematic approach aimed at better informing and counselling pregnant women about the implications and limitations of the triple test [16]. Similarly in Thailand, most pregnant women had inadequate knowledge of Down syndrome screening tests [17]. Pregnant women's mean score of knowledge of Down syndrome screening test was 20.6% [17]. A recent study conducted in Greece revealed that only 45% of the participant antenatal women had a good level of knowledge concerning the screening process for Down's syndrome [6]. The importance of education on knowledge regarding the screening process, rather than on the condition itself has been recommended [6]. In contrast, Danish group reported that the majority of the participants (nearly 90%) correctly identified the test that main condition being screened for [14]. However, the pregnant women were found less knowledgeable on test accuracy and drawbacks [14].

Termination of pregnancy for lethal fetal anomaly or anomaly causing severe neurodevelopment handicap is not yet legalised in Sri Lanka. Ministry of Health Sri Lanka has recently appointed a committee consisting of members of the Sri Lankan colleges of obstetricians, paediatricians and radiologists to look in to the possibility of suggesting legalization of termination of pregnancy in cases of severe fetal anomaly. In the absence of an option of termination of pregnancy one could question the justification of Down's syndrome screening. Even though the option of termination is not yet available for Down's syndrome, it is important to diagnose this condition prenatally as up to 40% of fetuses could have other structural abnormalities and it also helps parents to prepare emotionally and practically to take care of a disabled child [8]. Early detection of structural anomalies enables necessary early intervention at birth thereby optimising the outcome in these babies.

In conclusion, first trimester combined DS screening amongst both patients and staff in Sri Lanka is poor. In the context of this deficit in knowledge informed choice for DS combined screening would not be possible. Meeting this challenge would need to start with increasing the knowledge amongst staff so that the means would be available to disseminate knowledge to the wider patient and public populations.

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