

Sexual Health Education for Parents of Mild and Moderate Intellectually Challenged Children: Influence of Intervention Programme

KEYWORDS

Sexual Health Education (SHE), Practice, Intellectually Challenged Children (ICC).

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ABSTRACT Sexuality education is the core component in influencing the psychosocial development and social identity of children both the non-disabled and the disabled children. The non-disabled children receive information about sexuality education either form their parents, teachers, peers, friends and media. But the disabled children have to rely upon their parents alone for such information as their often perceived as asexual in nature. The intellectually challenged children because of their deficits in cognitive abilities take very long to perceive and comprehend the concept, find hard to differentiate between the good touch and bad touch, appropriate and inappropriate social behaviour etc. Therefore the onus of imparting sexuality education lies in the hands of the parents of these challenged children in order to help their children to become self- reliant. This will enable their challenged children to develop a social identity in the society. Thus the influence of intervention program on the practices of the parents of mild and moderate intellectually challenged children towards imparting sexual health education formed the focus of this study. A self-structured tool consisting of thirty two items with a five point rating was used. A purposive sampling technique was used in selecting the sample which consisted of 318 parents of the intellectually challenged children who were grouped into two 159 from experimental and 159 from control group. The study revealed that the parents of experimental group were clear, confident, and comfortable in imparting sexual health education to their children after undergoing an intervention programme.

Introduction

Sex and sexuality are generally considered taboo subjects, with personal values and religious beliefs often overshadowing the need to provide accessible, accurate information (Irwin, 1993). The sexual rights and needs of individuals with intellectual disabilities (ID) have received increased attention in the past several decades and their importance has been highlighted in a number of international policy documents (United Nations, 1993; 2006). The fact is that sexuality education still remains a highly sensitive and frequently neglected area of education to be imparted to the intellectually challenged children. The type and degree of intellectual disability very often obscures and shunts the mind of the parents in imparting sexual health education to their intellectually challenged children, as they perceive their ICC as asexual in nature.

Parents should play a major role in educating their ICC as they are unable to speak efficiently for themselves. Therefore it is incumbent on the parents that they should come forward to raise their child/children problems, find possible solutions and suggest ways and means to improve not only their child/children's psycho social skills but also their sexual health needs. Such demands require transfer of skills so that parents will be in a position to teach their ICC on the sexual health needs.

It is very important for the parents of ICC to understand that every child regardless of his/her disability is different and differ in their needs, age to learn, time, and the pace in which they learn. Therefore parents must be very effective in communicating with their children so that they can reinforce new concepts and skills at home through naturally occurring everyday situations (Wood, 2004). Intellectually challenged children do best in learning environments where visual aids are being used. These visual aids are

useful for helping ICC to understand what behaviours are expected of them. For instance, using charts is very effective in providing positive reinforcement for appropriate and on-task behaviour (Tammy Reynolds et. al., 2013). Parents should also be sure that the materials used/ aids used addresses both setting boundaries and respecting others' boundaries. For social norms to be dealt aptly the parents should rely on role plays and interactive sessions and exercises. Use of concrete teaching strategies will be effective and helpful (Dimple Keshav and Barbara Huberman, 2006).

If the concept is to be introduced to ICC, then it should be one step at a time, as this avoids overwhelming the child and provides a progressive, step-wise learning approach (Tammy Reynolds et. al., 2013). In addition, sexual health education can provide opportunities to develop appropriate sexual behaviour and reaffirm the message that their sexuality is respected (McCarthy and Thompson, 2001).

Since sexual health is a major, positive aspect of holistic health for a healthy living it should therefore be related to both the psychosocial and psychosexual needs which must be addressed with sound, scientific and factual information for which the parents must articulate very effectively/ efficiently. Effective sexual health programs should incorporate behavioural goals, use of materials that are age appropriate and based on the degree of disability, providing scientific facts, practical facts and the best practices. Practices are a method of preparation with perseverance to acquire and master the skill. This is possible only when parents make use of different types of practices to impart sexual health education. The best practices have significant role to play in preparing the ICC for their adult life. This is possible when the parents provide the right kind of information to their ICC from early years of life. Since ICC

also grow into social individual, concepts such as development, importance of developmental tasks, appropriate and inappropriate social behaviour, sexual behaviour, concept of good and bad touch, social milieu, importance of verbal and non- verbal communication, ascertaining the rights etc., should be explained to the ICC based on their age appropriateness and gender through the use of visual aids like books, flash cards, charts, narrations through storytelling, puppets and role play.

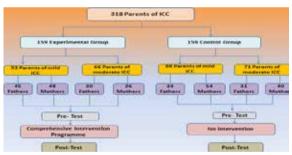
The practices should be based on the needs, situations and circumstances in which the child interacts in his/her day to day life. Further the parents should also keep in mind the degree of disability, while providing the practices, as the ICC have their own pace of learning. By doing so the ICC can be empowered to handle situations and protect himself/herself in any given social situations. This will further help him/her not only in sustaining the social relationships but also in getting him/her a better vocational placement.

Method

Objective: The study aimed to assess practices of parents of mild and moderate intellectually challenged children towards imparting sexual health education.

Methodology: The pretest-posttest method with an intervention program was used for the present study. The intervention program was planned to develop the best practices among the parents towards imparting sexual health education to mild and moderate intellectually challenged children.

Sampling: The parents of intellectually challenged children attending special schools in Bangalore city were identified for the present study. A purposive sampling technique was used to select the sample.



Sample Size:

Tool Used: A rating scale developed and standardized by the investigator was used to assess practices of the parents towards imparting sexual health education to mild and moderate intellectually challenged children. The tool consisted of 32 items related to practices on sexual health education for the parents of ICC viz sexual rights of ICC and responsibilities of the parents, parenting, need to teach the body parts and bodily functions, interpersonal relationship, public and private places, friendship skills, leisure time activities, need for verbal and non-verbal communication skills, self-awareness, confidence building, sexual behaviour, need for sexual expression, feelings and emotions, difference between good and bad touch etc.. The items were rated on 5 point scale that ranged from strongly disagree (1), disagree (2), uncertain (3), agree (4) and strongly agree (5), respectively. The developed tool was translated into regional language to evoke a better response.

Method of data collection

Pre – test: A pre-test was conducted to the parents of both experimental and control group to assess their practices towards imparting sexual health education. Prior permission was obtained from the principals and the parents of the ICC. They were informed about the purpose of the study. The investigator developed a personal rapport with the parents of mild and moderate intellectually challenged children in order to elicit accurate information and create a comfort zone.

Intervention programme: The parents of experimental group were given a comprehensive intervention programme spanning for seven weeks. The intervention was conducted on every Saturdays for duration of 3 hours. Concepts such as sexual rights of ICC and responsibilities of the parents, parenting, need to teach the body parts and bodily functions, interpersonal skills, myth and facts about masturbation, public and private places, friendship skills, need for verbal and non- verbal communication skills, self- awareness, confidence building, sexual behaviour, need for sexual expression, feelings and emotions, difference between good and bad touch etc,. The intervention programme was followed by group discussion and group activities. The parents were introduced to the concepts through various techniques such as interactive sessions, role play, puppet show, video clippings, and visual aids. In order to encourage and motivate the parents in effective participation, they were rewarded with incentives whenever they volunteered to share their views and were sportive in their interaction. A feedback of the intervention program was also obtained from the parents at the end of each session.

Post -test: A post- test was conducted to the parents of both control group and experimental group to assess their change in practices after undergoing the intervention program.

Statistical Analysis: Descriptive statistical analysis was used to analyze the data on the objective formulated.

Results and Discussion

Table 1: Practice of the parents of intellectually challenged children towards imparting sexual health education

Practice	Experimental Group				Control Group			
	Pre	Post	t value	P value	Pre	Post	t value	P value
Father-mild	59.14±24.09	133.42±6.89	18.433	<0.001**	59.32±23.89	59.26±24.3	0.267	0.791
Father-moderate	59.28±24.13	131.73±9.64	13.867	<0.001**	60±24.13	57.45±24.34	0.406	0.688
Mother- mild	60.39±24.2	133.4±10.71	19.423	<0.001**	59.38±23.97	60.44±23.5	0.437	0.664
Mother- moderate	59.53±24.08	132.78±12.1	16.663	<0.001**	59.88±24.01	58.03±23.69	0.356	0.724

^{**} Strongly Significant

Recognition of the sexuality and sexual health education needs of intellectually challenged children can be difficult for parents who look after, care and work for well-being. Yet, there has been growing evidence of the need to address these issues by the parents who should move outside the comfort zones, so that they respond with integrity and sensitivity to this much neglected area.

Table 1 and figure 1 clearly indicates that at the time of pre- test assessment the parents' practices towards imparting sexual health education was similar between both the experimental group and control group. At the time of post-test a greater change in the practices of the parents of mild and moderate ICC of experimental group towards imparting SHE was observed, with the mean value being 133.42 (SD-6.89), 131.73 (SD-9.64) and the P value being at (P=<0.001**) strongly significant. This could be attributed to the concepts to which they were introduced at the time of intervention programme like sexual rights of ICC, parenting, importance of teaching about the body parts and bodily functions from early years of age to the ICC, personal hygiene, myth and facts about masturbation, difference between public and private places, friendship skills, communication skills, social etiquette, self- awareness, need for sexual expression and the need for use of colloquial language in imparting sexual health education. Further research has shown that general skills such as decision making, problem solving as well as specific techniques such as refusal skills or assertiveness should be taught to the ICC. Hence in the present study group discussion, group activities, interactive sessions, TV show, role play, use of visual aids etc. played a crucial role in helping the parents to understand the need and the facts of imparting sexual health education.

The literature also suggests that many people with an intellectual disability are receiving little sexuality education, with staff and caretakers either ill-prepared or reluctant to address issues of sexuality. Although there is greater emphasis on the legal rights of persons with intellectual disabilities, there is very little information on the sexual knowledge or feelings of individuals with intellectual disability or the effectiveness of educational programmes to alter this knowledge and feelings (McCabe and Schreck 1992, Garwood and McCabe, 2000).

Therefore the goal of sexual health education should be to help the parents of ICC to understand that it is important that their child develop self –concept, respect for self and others, need for interpersonal and social relationship. Sexual health education should be focused on the positive aspects of human sexuality. Further it should aim at increasing knowledge through the use of teaching aids which needs to be culturally specific, appropriate to age and degree of disability.

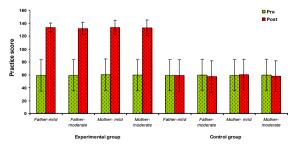


Figure 1: Practice of the parents of intellectually challenged children towards imparting sexual health education

Table 2: Pre-Post outcome scores of parents of experimental group and control group on their practices towards imparting sexual health education

Practices	Experimental Group	Control Group	t value	P value
Pre-test score	59.61±24.01	59.57±23.86	0.001	0.988
Post-test score	80.77±5.56	37.59±13.25	37.868	<0.001**
Outcome (pre-post)	72.23±26.29	-0.52±31.81	22.26	<0.001**

** Strongly Significant

Table 2 depicts the mean scores of pre, post and outcome (pre-post) assessment on the practices of parents of both experimental group and control group.

The pre-test mean scores of the parents of experimental group is 59.61(SD-24.01) in comparison to the parents of control group 59.57 (SD-23.86) the P value being (P=0.988) non-significant. Whereas in the post-test the experimental group have shown a tremendous improvement with mean scores being 80.77 (SD-5.56) when compared to the control group who has shown no change in their practice aspects with the mean score being 37.59 (SD-13.25), which was statistically strongly significant. During post assessment data majority of parents of experimental group expressed that they had made a beginning in using some simple techniques to teach their ICC about the self -awareness, social etiquette, personal hygiene, social behavior and the difference between good and bad touch. The findings of the present study is in concordance with the study carried out by Lefkowitz et al., (2000), mothers who attended an intervention to enhance interactive communication skill reduced their amount of speaking, asked more open-ended questions, acted less judgmental, and discussed about sexuality more than mothers of the control group.

Conclusion

Self -awareness and self- identity contribute to the overall development of ICC and also attributes to their sexual development. The concept of self, self- awareness and self- identity should therefore begin during the early years of life by enabling the ICC to understand who he/she is, his/her roles, skill, psychosocial behaviour and traits. Since ICC lack social understanding, they may engage in inappropriate social behaviours. Therefore teaching the aspects of 'self', 'social self' and 'appropriate sexual behaviours requires a lot of devotion and dedication from the parents of ICC. As ICC are slow in comprehending the concept because of their degree of disability, age and attention span in learning a particular concept, therefore it is imperative for the parents of ICC to teach and train their ICC on different aspects of sexual health through the use of appropriate teaching aids in a gradual and step by step manner. Such efforts can contribute to their psychosocial and psychosexual development and with the parental efforts SHE can be an ongoing process.

Acknowledgement: We sincerely thank University Grants Commission, New Delhi, for funding the Major Research Project in Home Science

Volume: 4 | Issue: 8 | August 2014 | ISSN - 2249-555X

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