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Empirical Analysis of Sterilization of Mentally Handicapped Individuals in the United States

Abstract

Sterilization of mentally handicapped individuals occurs today despite little consensus in the medical community as to when sterilization is appropriate (Zurawin & Paransky, 2003). In addition, each state has different laws regarding sterilization of the mentally handicapped. Thus, nurses and nurse practitioners must navigate the complex social issues and legal uncertainties related to sterilization of the mentally handicapped. The purpose of this paper is to answer the following question: What is the current social climate associated with sterilization of mentally handicapped individuals?

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Heather Begun, BSN

Abstract

Sterilization of mentally handicapped individuals occurs today despite little consensus in the medical community as to when sterilization is appropriate (Zurawin & Paransky, 2003). In addition, each state has different laws regarding sterilization of the mentally handicapped. Thus, nurses and nurse practitioners must navigate the complex social issues and legal uncertainties related to sterilization of the mentally handicapped. The purpose of this paper is to answer the following question: What is the current social climate associated with sterilization of mentally handicapped individuals?

In the United States, sterilization of the mentally handicapped has a long history. For many years, involuntary sterilization was legal. Consequently, many mentally handicapped individuals were forced against their will to have medical procedures rendering them sterile. Today, there is no standard law or policy for all states regarding the sterilization of a mentally handicapped person who is unable to give informed consent. Some states allow sterilization under certain circumstances, others do not allow this procedure at all, and still other states laws are silent on the issue (Zurawin & Paransky, 2003). In addition, since the 1980's, medical journals have published many articles discussing the issues of sterilization, yet, only a small amount of published research has addressed the topic of sterilization of the mentally handicapped.

The Ashley X case demonstrates that the issue of sterilization of the mentally handicapped continues today. In this case, a nine-year-old severely mentally handicapped girl had her uterus and breast tissue removed in addition to receiving large doses of estrogen to halt her growth (Tanner, 2007). Her parents made this request because they feared she would experience discomfort with her periods, possibly develop breast cancer, and grow into a size that would make it too difficult for them to care for her (Tanner). Thus, the Ashley X case demonstrates that nurses and nurse practitioners today still must face the complex issues surrounding sterilization when working with mentally handicapped patients. However, nurses and nurse practitioners may remain uncertain as to what their state law allows and what current criteria are for when or if sterilization may be performed. As a result, this paper will address the following question: What is the

today's social climate associated with sterilization of mentally handicapped individuals?

Background

Mental retardation

According to the DSM-IV, mental retardation is characterized by "sub average intellectual functioning (an IQ of 70 or below) with onset before the age of 18 and concurrent deficits in adaptive functioning in at least two of the following skill areas: communication, self-care, home living, social/interpersonal skills, use of community resources, self direction, functional academic skills, work, leisure, health and safety" (Paransky & Zurawin, 2003). Mildly retarded individuals have an IQ between 50 to 70, and may be capable of grade school reading and performing semiskilled labor (Paransky & Zurawin, 2003). Individuals with an IQ of 35 to 55 are considered moderately retarded while those with an IQ less than 35 are defined as severely retarded (Paransky & Zurawin, 2003). Approximately 1% of the general population is considered mentally retarded (Paransky & Zurawin, 2003). This paper will include both children and adults in the category of mental handicap.

Sterilization

For the purposes of this paper, sterilization refers to the surgical methods of contraception such as tubal ligation, hysterectomy or vasectomy. There are also distinctions between compulsory, voluntary, and involuntary sterilization. Sterilization is considered compulsory when it is required by law (Diekema, 2003). If a competent individual freely chooses to be sterilized to limit his or her ability to have children in the future, this is considered voluntary sterilization (Diekema, 2003). Involuntary sterilization is the sterilization of

an individual incapable of providing consent to the procedure (Diekema, 2003).

Legality

In order to understand the issue of sterilization of the mentally handicapped, one must first review the legal history in the United States. State law regarding sterilization of “persons mentally unable to give consent” (Australian Journal of Public Health [AJPH], 1992) has passed through several stages. The first movement began during the beginning of the 20th century when mentally handicapped individuals were often confined to institutions (“Reproductive Health”, 1997). At this time, due to lack of understanding of genetics, the belief that sterilization was necessary to prevent “genetic transmission of mental retardation” (“Reproductive Health”) was prevalent. Involuntary sterilization, or the eugenics movement, first became state law in 1907 when Indiana enacted eugenics sterilization (AJPH, 1992). Despite Indiana’s law being struck down as unconstitutional by the Indiana Supreme Court in 1921, by 1937 the majority of states had some form of eugenics sterilization law in place (AJPH, 1992).

At the same time, United States federal courts were asked to consider the issue of involuntary sterilization. Specifically, in 1927, in *Buck vs. Bell*, the United States Supreme Court determined involuntary sterilization of “probable potential parent of socially inadequate offspring” (Baker, Buck, Engro, Renda & Smetanka, 1997) was not unconstitutional. Then in 1942, the Supreme Court challenged the law on mandatory sterilization in *Skinner vs. Oklahoma* and overturned its ruling in *Buck vs. Bell* (AJPH, 1992). The court recognized the inherent right of procreation for all individuals (“Reproductive Health”, 1997). Following that ruling, consent for involuntary sterilization became difficult for parents/guardians to obtain on behalf of their mentally handicapped family members, whether or not the mentally handicapped person was a minor (under 18 years of age) (Diekema, 2003). Beginning in the 1960’s, parents began filing lawsuits requesting sterilization stating it was essential to the well-being of the mentally handicapped individual and the family caring for him or her. Specifically, it was argued that sterilization protected the individual and

the family from menstruation fears, pregnancy risks and parenthood burdens (Diekema, 2003).

Since then, 39 states have established either statutes or case law to address the issue of sterilization. However, due to widespread sterilization abuses in the past, these state laws vary widely regarding when or if a mentally handicapped person can be sterilized (Paransky & Zurawin, 2003). Some states prohibit sterilization consent by a third party altogether while others permit it under certain circumstances (Paransky & Zurawin). If a state allows sterilization in certain circumstances, the parental interest in protecting the mentally handicapped child (regardless of the child’s age) from unwanted pregnancy or inconvenience of menstrual hygiene are not considered (Paransky & Zurawin). In fact, current law in many states assigns a court appointed guardian, assuming the parents’ best interests are in conflict with their daughters’ (Paransky & Zurawin). However, while these laws are protective, they can inhibit mentally handicapped patients from receiving medical care that is accessible and used by approximately 190 million couples worldwide (Zurawin & Paransky, 2003). Ultimately, these varied legal responses give patients limited access to the same medical procedure (Paransky & Zurawin).

Ethical Issues

When discussing any surgical procedure, like sterilization, the general ethical principles of autonomy and beneficence must be part of the discussion. Autonomy, or the right to self-determination, is the underlying basis for informed consent and supports a patient’s right to determine what will be done with their own person (American Nurses Association [ANA], n.d.). But in the case of a mentally handicapped patient who is not capable of informed consent, a third party must make beneficence-based decisions regarding medical treatment (American College of Obstetrics and Gynecology, 2003). In this case, beneficence is the ethical principle where a third party must protect the patient from harm and promote good (ANA, n.d.). In the case of sterilization of mentally handicapped individuals, one must consider if the procedure promotes the patient’s welfare or is the greater good for the patient served by alternatives to sterilization.

Methods

The literature search was designed to find historical summaries of legal issues, historical and current research studies, and ethical analyses discussing the issues and trends regarding the sterilization of the mentally handicapped. Four online databases were used for this search: Cumulative Index of Nursing and Allied Health (CINAHL), Medline (PubMed), ISI Web of Science and the Cochrane Collaboration Databases.

The keywords “sterilization AND mentally handicapped” with the limits of English and human were used for both CINAHL and PubMed. Because there is little current research on the topic, there were no date limits placed. The search yielded 364 articles, with many of them being more than 15 years old. From these search, 32 articles were identified as related to sterilization and/or health care practices. Additional searches using the above mentioned limits were performed using keywords “contraception AND mentally handicapped”, “developmentally disabled AND sterilization”, “developmentally disabled AND contraception”, and “growth attenuation”. From these searches, only four articles relating to sterilization were found that had not been previously identified. Based upon review of previous searches, one Michigan physician’s name appeared as an author of numerous articles. As a result, a search was made using the keywords “Elkins AND Michigan” but did not produce any relevant articles not previously identified.

Finally, a search of the Cochrane Collaboration Databases and the ISI Web of Science was performed using the key words “sterilization”, “sterilization and mentally handicapped”, “Elkins, T.”, and “Chamberlain”. However, upon review of all the citations, there were no new relevant articles retrieved.

Literature Review and Analysis

Historical Research (1984-1994)

From 1984 to 1997, many opinion articles and legal summaries were published discussing the issues surrounding sterilization of the mentally handicapped. However, only a small number of research studies were published on the subject. These early studies were the first to quantify the issues of sterilization (Chamberlain, Rauh, Passer, McGrath, & Burket, 1984; Elkins, Gafford, Wilks, Muram, & Golden, 1986;

Elkins, Hoyle, Darnton, McNeeley, & Heaton, 1988; Passer, Rauh, Chamberlain, McGrath, & Burket, 1984; Patterson-Keels, Quint, Brown, Larson, & Elkins, 1994). Overall, the focus of these studies deals with parental views of sterilization, reasons for requests for sterilization and sexual issues faced by mentally handicapped individuals.

Parental views and reasons for requests for sterilization

In the 1980’s, several studies investigated parental views and parental reasons for requesting sterilization. In these quantitative studies, it was found that parents had many fears and concerns about menstrual hygiene, inappropriate sexual behavior (i.e.; kissing, touching), fear of pregnancy, fear of sexual abuse and uncertainty about the efficacy of birth control methods (Patterson-Keels et al., 1994; Elkins et al., 1986). Such fears and concerns were found to lead to requests for sterilization (Patterson-Keels et al, 1994; Elkins et al., 1986) and for 54% of parents, the fear of pregnancy outweighed any reservations about sterilization (Patterson-Keels, 1994).

Another quantitative study by Passer et al. (1984) found that 46% of parents considered sterilization for their mentally handicapped daughters, 85% of parents favored legal statutes enabling sterilization of a mentally handicapped person and 87% of parents wanted to be involved in the decision to sterilize or not. Furthermore, in 1994, Patterson-Keels et al. found that 97% of parents wanted assistance with the decision of sterilization and had little knowledge of state laws.

Finally, in a descriptive study by Elkins et al., a Michigan clinic received 20 parental requests for sterilization (1988). After each parent consulted with an ethics committee to discuss alternatives to sterilization, state laws and other support issues, only 5 cases were recommended for sterilization. Thus, this study demonstrates how increased parental support can decrease requests for sterilization.

These studies underscore not only the parents’ need for more information and support for the care of their mentally handicapped family members but also that this lack of knowledge and support leads to their request for sterilization. However, while these studies are the only studies to address parental views and continue to be referenced in relevant articles today, all

four of these studies had several limitations. First, all the studies used small, convenience samples in limited geographic areas, therefore limiting the generalizability of their results. In addition, both studies by Patterson-Keels et al. (1994) and Passer et al. (1984) used surveys to collect data yet the investigators failed to report on reliability and validity of the survey and how the measures were developed. However, despite the limitations of the studies, the research was the first of its kind and addressed important parental concerns and views of sterilization.

Sexuality Issues

The prevalence of sexual activity in the mentally handicapped population had not been quantified prior to 1984. However, in 1984, a survey study by Chamberlain et al. reported 34% of mentally handicapped patients had sexual intercourse at least once with 43% of those sexually active patients becoming pregnant. Furthermore, a 1986 descriptive study by Elkins et al. found that 30 out of 65 patients were sexually active. In addition, both of these studies reported prevalence of sexual abuse in the mentally handicapped population; 33 out of 65 in Elkins et al. (1986) and 25% in Chamberlain et al. (1984). Both of these studies quantify what many parents in previous studies had indicated – that their mentally handicapped family members were in fact sexually active and/or at risk for sexual abuse and pregnancy.

Again, both of these studies continue to be referenced in current literature because they are the only studies to measure these statistics. However, the Chamberlain et al. (1984) study also surveyed a small, convenience sample (n=87) from a limited geographic area and failed to report on the reliability or validity of the survey. The Elkins et al. (1986) study was a descriptive study of a small population (n=65) from one clinic in Michigan. As a result, both of these studies have limited generalizability.

Current Research (2000-2004)

From 1984 to 1994, the focus of the published research was to quantify issues surrounding sterilization of mentally handicapped individuals and parental views. From 1994 to 2000, while many opinion articles and legal summaries were written, a large gap exists in the research with no relevant publications during

that time frame. Since 2000, four research articles and one ethical analysis have been published that deal with some issue of sterilization. These articles address different topics surrounding sterilization. However, overall, the current research trends have begun to move away from raising awareness of parental issues and mental handicapped individuals sexual needs to now measuring inconsistencies of when sterilization is allowed and proposing a means to measure when to perform sterilization.

With varying state laws and attitudes regarding sterilization both in the United States and abroad, two of the current studies aim to quantify the environmental influence on sterilization rates (Servais, Jacques, Leach, Conod, Hoyois, Dan et al., 2002; Servais, Leach, Jacques & Roussaux, 2004). For example, in a 2002 study in Belgium, Servais et al. used a quantitative survey design to assess the type of contraception used by 397 mentally handicapped individuals in institutions as compared to the general population. The study found that contraception in women with mental handicap is characterized by greater use of depotmedroxyprogesterone (DMPA) and sterilization when compared to the general population (Servais et al, 2002). In addition, the study found that the choice of contraception management was more determined by institutional policy and not health concerns or needs of the patient (Servais et al., 2002). In 2004, Servais et al. followed up the first study with a second publication, using the same data from 2002, addressing the prevalence of sterilization and to determine social and medical factors associated with them. The sterilization rates of women with mental disability were 22% versus the general population rate of 7% in Belgium. In addition, this study found that there was no significant difference in sterilization rates among women based on level of disability but rather women in institutions were more likely to be sterilized if she attends a facility where sexual intercourse is prohibited versus a facility where sexual intercourse is allowed (38% vs. 12.3%, $P < 0.001$). These two studies are relevant because they underscore the current lack of individualized gynecological care of mentally handicapped women (Servais et al., 2002; Servais et al., 2004). In addition, these studies demonstrate

that the sterilization in mentally handicapped women differ significantly depending on the environment the women resides (Servais et al., 2002; Servais et al., 2004). However, while this two part study was very well designed and was the first to use a large sample size, it is difficult to generalize the study's results to the United States population because mentally handicapped individuals are now living in their communities rather than in institutions (Servais, 2006).

Additional studies also attempt to address when sterilization is appropriate and what tests should be used to assess ability to consent (Diekema, 2003; Kennedy, 2003). In 2003, Diekema argues in his ethical analysis that there are in fact situations when sterilization is ethical. Diekema describes sterilization as ethical when a person lacks the capacity for reproductive decision making, ability to raise a child, and ability to provide valid consent for marriage. Also, if the procedure is absolutely necessary, those seeking sterilization must present clear evidence that it is in the patients best interest, and that alternatives are not in the patient's best interest (2003). However, the analysis does not address how to support or educate families nor does it suggest how medical providers are to assess these capacities and requirements.

In 2003, Kennedy used a correlational design to quantify the best mental assessment test to determine ability to consent to sexual activity. In this study, Kennedy illustrates that there are currently no consistent guidelines in place, either legally or clinically, to evaluate for competency for sexual consent and much variation exists between states (2003). Of particular importance is Kennedy's identification of the current clinical practice of assessing competency. Specifically, clinical judgment of consent to sexual activity varies from practitioner to practitioner with individuals basing decisions on a range of criteria (Kennedy, 2003). In addition, Kennedy determines that neuropsychological measures classified an individuals ability to consent to sexual activity with 85.5% ($P < 0.001$) versus current measures such as assessing understanding of biological function and responsibility of pregnancy or knowing appropriate locations to engage in sexual activity which had an accuracy of 72.1% ($P < 0.001$) (2003). Several limitations exist which decrease the generalizability of

Kennedy's study. Specifically, the study uses a small, convenience sample of 64 mentally handicapped individuals from one geographic location.

Finally, prior to 2000, only one study mentioned sterilization issues of two male mentally handicapped individuals (Elkins et al., 1988). However, in 2000, Carlson, Taylor, & Wilson designed a survey study to specifically look at awareness in legal and medical organizations of male sterilization using surgery or hormonal control. This study was the first study to attempt to evaluate any aspect of sterilization of male mentally handicapped individuals and thus raises awareness to the lack of knowledge in this area. However, this study was very poorly designed with very unclear and inconclusive results. In addition, a low response rate, no reliability or validity of the survey reported, and a small sample size ($n=51$) make any results difficult to generalize to a broader population.

Discussion

Legal issues surrounding sterilization vary from state to state and leave many parents not only unclear of their state laws but also unable to advocate for their child. In addition, historical research clearly demonstrated not only that parental fears and concerns of pregnancy, sexual activity and abuse lead to the request for sterilization but also that many of their fears and concerns were legitimate (Patterson-Keels et al., 1994; Elkins et al., 1988; Elkins et al., 1986; Passer et al., 1984). Furthermore, the historical studies illustrated that mentally handicapped individuals are sexually active (Chamberlain et al., 1984; Elkins et al., 1986). More current research has shifted to primarily focus on the environmental influence of sterilization decisions and the lack of criteria to guide decision making about sterilization (Servais et al., 2002; Servais et al., 2004; Diekema, 2003; Kennedy, 2003). Of particular importance is the research results which indicate the not only are women's individual needs not a part of the decision process but that institutional policy alone determines sterilization outcomes (Servais et al., 2002). In addition, virtually no research exists on the issues of sterilization of mentally handicapped men (Carlson et al, 2000). Finally, there is a need for some set of evidenced based criteria to assist and guide health professionals in assessing ability to consent to

sexual activity (Kennedy, 2003).

While the above mentioned studies all raise important points related to the sterilization of mentally handicapped individuals, all of the studies have limitations that significantly impact the ability to generalize the results to a larger population and effect evidence based change in practice. Most of the studies used surveys without discussing or assessing reliability and validity or how the measures were developed. Furthermore, all but two of the studies used extremely small convenience samples from small geographic areas, thus, limiting the generalizability of the results. Another important limitation of the body of research is that most of the historical studies were co-authored by Dr. Elkins, while two out of five of the current studies were co-authored by Servais. When the majority of existing research is produced by a limited number of investigators, one has to be cautious in broadly applying the results of the studies.

Recommendations

In order to improve our current understanding and treatment of mentally handicapped individuals for whom sterilization is requested, both qualitative and quantitative research must be conducted. First, parental concerns and support are critical when providing care to the mentally handicapped. As demonstrated by Elkins et al. (1988), when parental concerns and needs in caring for their child are addressed, the request for and incidence of sterilization was significantly reduced. Therefore, in order to develop a more accurate understanding of parental issues, concerns, and appropriate questions to ask, qualitative research is needed to explore parental fears, concerns and what they perceive as important in the care of their family member. Once a more accurate knowledge base exists surrounding these parental issues, several large, multi-centered quantitative studies can incorporate the knowledge gained in the qualitative work and conduct research to more accurately quantify current sexuality issues facing families with mentally handicapped individuals and how to improve the care provided to the entire family. In addition, this research needs to more accurately assess the prevalence of sterilization in both women and men and also assess the effectiveness of alternatives to sterilization. Furthermore, sexual

abuse has been reported in earlier studies as not only occurring but also being a motive for families to request sterilization. A national study to address these concerns and to assess the current prevalence of sexual abuse in this population and how to better prevent this type of abuse is warranted. Finally, as demonstrated in more recent studies, environmental influences have an impact on the prevalence of sterilization. As a result, a large multi-centered study that assessed prevalence of sterilization in various states may better help assess the influence these laws have on access and utilization of sterilization in the mentally handicapped community. Perhaps through larger and more rigorous studies, clinical practice guidelines can be established to clarify this very complex and difficult issue.

Nursing Implications

Currently, there is no existing body of research in nursing on sterilization of mentally handicapped individuals. Despite the fact that nurses are the health care providers on the front line, there are no criteria, guidelines or suggestions of how to handle requests for sterilization, what the state laws allow, or how to support families who make such requests. Furthermore, even with the limited research on sterilization, ACOG and other medical journals have published articles that attempt to establish some understanding of the issues and laws (ACOG, 2003; Paransky and Zurawin, 2003; Denkens, Nys & Stuer, 1999). However, there are no relevant articles in any of the nursing journals. Therefore, an opportunity exists for nurses to not only expand upon and improve the quality of research on the issues of sterilization but also to establish guidelines for the care of these patients.

Until clinical practice can be changed by evidenced-based practice, nurses and nurse practitioners can better serve this population by facilitating continual support and discussion of both the sexual and ethical issues surrounding sexual health and sterilization with parents/caregivers. To assist nurses in this process, educational training should be established to help nurses understand and discuss the relevant sexual issues, to ensure they are knowledgeable of state laws and current research regarding sterilization and to discuss how to handle the ethical issues of informed consent and beneficence with this population. In

addition, a multidisciplinary approach including nurses, physicians, social workers, the patient and the parent/caregiver should be used to provide comprehensive sexual health care to the mentally handicapped patient and to address the complex ethical and legal issue of sterilization (Servais, 2006). Through a collaborative approach, nurses can provide higher quality gynecologic health care to this vulnerable population.

Conclusions

Currently, there is little consensus in the medical community as to when sterilization of mentally handicapped patients is appropriate (Zurawin & Paransky, 2003). In addition, each state has different laws regarding sterilization of the mentally handicapped (Paransky & Zurawin, 2003). While a small body of research exists on sterilization, the studies limitations preclude them from affecting broad change in clinical practice. Furthermore, nurses have not begun to research or address the difficult and complex issue of sterilization yet the issue continues today as evidenced by the Ashley X case. With little guidance and little research on appropriate treatment and steps in advocating for their mentally handicapped patients, nurses are put in the difficult position of trying to understand confusing laws, provide beneficent care, and better educate on alternatives to sterilization. Therefore, as nurses, we must advance the current knowledge base of the issues surrounding sterilization by conducting high-quality, rigorous studies that can change clinical practice to better serve not only mentally handicapped patients but also their families.

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