Cigarette Smoking, and the Use of Tobacco Products, by Persons With Developmental Disabilities


1Case Western Reserve University School of Medicine
2Department of Psychology, Youngstown Developmental Center
3Medical College of Virginia

Smoking and tobacco use is the leading cause of preventable death, costing 400,000 lives and 100 billion dollars annually in the United States. Only a few reports describe smoking in persons with developmental disabilities; most concern smoking prevalence or smoking-related illnesses. Smoking has previously been described as a personal choice, but nicotine addiction may preclude truly informed choice. The authors present two smokers with developmental disability, and provide a framework for assessing the competence of individuals with MR/DD to smoke. They conclude that only those persons with developmental disability who can demonstrate the highest level of competence be permitted to smoke.

Keywords: addiction, cigarettes, consent capacity, developmental disability, intellectual disability.
BACKGROUND

Relatively little has been written on the subject of cigarette-smoking, and other uses of tobacco products, by persons with developmental disabilities (DD). Some research has focused on the prevalence of smoking in various residential settings, or attempted to characterize policies regarding smoking and the use of tobacco products within institutions, vocational settings, community residences, residential programs, etc. Several studies have focused on smoking-related illnesses as a subset of other chronic diseases in persons with DD, attempting to compare incidence and prevalence rates to those found in the general population. The latter has often been part of a broader focus on the health and healthcare needs of persons with DD. Such interest has resulted in the recent convening of a national conference by the United States’ Surgeon General, to examine and make recommendations regarding health care problems, needs, and mortality in persons with developmental disability. In its comprehensive report, the conference mentions smoking cessation programs as a goal involving the integration of “health promotion” into the community environment of persons with mental retardation/developmental disabilities (MR/DD). It also recommends the provision of “training in health care, including healthy habits, for personal care attendants and other caregivers.”

A review of major texts addressing either the health care and mental health, or vocational, residential, or recreational lives of persons with mental retardation, revealed few references to cigarette smoking. Remarkably little is known, for example, regarding the prevalence of cigarette smoking by persons living in various residential settings (institutions; community residences; supported living; with families; independently). Little research exists attempting to characterize whether for persons with MR/DD, smoking appears to be co-morbid with other psychiatric or behavioral disorders (as has been outlined in recent studies noting increased rates of cigarette smoking among certain sub-populations of individuals with mental illness). Finally, little is known regarding the attitudes, or policies and practices based on those attitudes, of agencies responsible for providing vocational, residential or other services to individuals with DD.

LITERATURE REVIEW

The sparse literature regarding the use of tobacco products by persons with MR/DD can be divided into three areas:

1. Surveys of smoking prevalence by individuals with MR/DD, or smoking as it relates to disease production.
2. Descriptions of smoking policies or practices in various residential/vocational settings.
3. Attempts to educate persons with MR/DD regarding the risks of smoking, and/or undertake and complete smoking cessation programs.

SMOKING PREVALENCE

Most of the health-related reports are surveys of smoking prevalence and use of tobacco products among persons with MR/DD living in various residential settings. In a study of cardiovascular risk factors among 329 persons with MR/DD, Rimmer et al. found low rates of smoking among those living in large residential facilities (2.2%), and with natural families (4.7%), compared to those living in community residences (10.2%), although the latter sample size was smaller than the other two residential settings.

Burtnet et al. specifically observed patterns of tobacco use among 749 adults with MR/DD living in a single state developmental center, comprised of 43 separate residences. Use of tobacco products included smoking of cigarettes, cigars, chewing tobacco, using snuff, or chewing/ingesting cigarette butts. The majority of subjects (627 of 749; 84%) were persons with severe/profound retardation; of these, only 27/627 (4.3%) used tobacco products. However, of the 122 persons with mild or moderate MR/DD, 25 (20.5%) were tobacco users. The authors noted that this percentage was not dissimilar to percentages of use commonly reported in the general US population.

Taking a community perspective, McDermott et al. compared rates and patterns of chronic disease among adults with MR/DD living in the community to a matched sample of adults without MR/DD with either Medicaid or private health insurance. In their sample, only 3.3% of adults with MR/DD were listed as “chronic smokers,”

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compared to 13.1% of Medicaid recipients and 8.8% of those with private insurance.

Hymowitz et al.\textsuperscript{13} reported that 25 of 136 adults (18%) with MR/DD and mental illness seen in a specialized DD clinic identified themselves (or were identified) as smokers. In their sample, the percentages were highest for those with mild retardation (30%) and borderline intellectual function (37%). The authors noted that these rates were similar to that found in the general population, and speculated that persons with mild disability or borderline intellectual function would likely be more susceptible to influence by tobacco advertising. This might be particularly true as it might relate to a view of smoking as something done by mature, competent adults.

Tracy and Hosken\textsuperscript{25} examined tobacco use in a small sample of adults with MR/DD living independently in the community in Australia. The authors excluded individuals living in institutions or community residences, feeling that direct support professionals would significantly influence their smoking behavior and decisions. In their fairly random sample, 13 of 36 subjects (36%) were current smokers, and another 9 of 36 subjects (25%) were identified as former smokers.

In a comprehensive study of smoking by and relating to individuals with MR/DD, Minihan\textsuperscript{17} surveyed 131 Massachusetts programs and institutions serving persons with MR/DD, comprising over 1,200 residential sites. The overall prevalence of smoking by persons with MR/DD in all programs was 12.7%, compared to a smoking prevalence of 34.4% of employees working in those programs. Smoking prevalence was higher in community agencies that were vendor-operated (15.8%), compared to state-operated community settings (9.7%) and state-operated institutions (6.8%).

Robertson et al.\textsuperscript{22} looked at the prevalence of lifestyle-related risk factors for poor health in a large sample (500) of persons with DD of variable ability living in a variety of residential settings in the United Kingdom. Smoking was less prevalent than other health-risk behaviors (obesity, poor diet, physical inactivity, etc.), and was associated with greater ability and a less restrictive residential setting.

Finally, in a recent large-scale study of cancer incidence in persons with MR/DD in Finland, Patja, et al.\textsuperscript{19} found that cancer rates were similar to those in the general population, in spite of a lower prevalence of smoking. The authors found only a 9% prevalence of smoking in a separate sample of adults with MR/DD, and concluded that the lower incidence of smoking-related cancer was consistent with this finding.

**SMOKING POLICY, EDUCATION AND TREATMENT**

There are few reports of smoking policies, or attempts to address smoking in persons with MR/DD, either with smoking cessation education or with specific treatment. Tyler and Bourguet\textsuperscript{26} included smoking cessation counseling among other recommended health maintenance practices in a report describing the medical care of 21 adults with MR/DD seen in a family practice clinic in the first year after de-institutionalization. In their sample, three were smokers and they all had smoking-related health problems. With identification of smoking as a health concern by the physician, one of the three was able to stop smoking and the other two halved their use of cigarettes. The authors noted that counseling for smoking cessation in persons with MR/DD is complicated by issues of patient rights and others’ rights to a healthier (smoke-free) environment. They also questioned whether some individuals with MR/DD could be expected to understand the risks of smoking.

Peine et al.\textsuperscript{20} described their treatment of two middle-aged male smokers with MR/DD, using a non-aversive behavioral technique. The authors noted that 4% of the adult population of the state developmental center where the men lived were smokers, and that none of the smokers in this setting expressed concern regarding the long-term health consequences of smoking, or a desire to discontinue smoking. The two men (one with moderate and one with severe MR/DD) had a long history of maladaptive behavior associated with procuring cigarettes and/or aggression when cigarettes were not available. Both had been smoking for greater than 20 years. Both men agreed to a program that initially made smoking contingent on the absence of maladaptive behavior. After a lengthy baseline (in which each man could earn cigarettes for every waking hour without maladaptive behavior), the men began a “spinner” program. In this program, they were able to spin an arrow each hour, with the possibility of the arrow landing on a picture of a cigarette, or several alternate reinforcers. These included coffee, tea, candy, juice, cola, a magazine, or tokens that could be spent on other items. Over nearly two years of operation, both men substantially reduced the number of cigarettes smoked. The authors could not
determine whether the “active ingredients” in the program were the alternate choices, the spinner program itself, the extra staff attention it provided, or some combination of these factors. They did note that both men continued to have access in their environment to other illicit sources of cigarettes, but showed less interest over the months. It would appear that creative approaches to provide alternative reward systems can bring about significant change. It must be noted that the gradual decline in cigarette use would have substantially decreased behavioral problems caused by discomfort associated with nicotine withdrawal. In spite of their apparent success, the authors concluded that, as persons with MR/DD are given more lifestyle choices, the use of cigarettes might increase, particularly in community settings where it is more difficult to mandate smoke-free environments.

Tracy and Hosken, in a follow-up to their smoking prevalence study in Australia, attempted to provide a smoking cessation program for adults with MR/DD who were identified in the initial study. After organizing a course and modifying a previously successful smoking cessation program for the general population, the authors found little actual interest among the developmentally disabled individuals who had earlier voiced some intention to stop smoking. They were able to begin a smoking education program for a different group of young adults with MR/DD. Of 11 students completing the course, three stopped smoking and three others significantly decreased their use. At the end, all 11 expressed concern about the health effects of smoking.

The Case of Mr. A

Mr. A is a 73-year-old man with severe mental retardation. His medical record indicated that he began to have convulsions at age seven months, thought to be caused by encephalitis. His behavior from that point was described to be hyperactive, aggressive and self-injurious. He was determined to be “feeble-minded” and was committed to a state-operated residential school at the age of 10. He was transferred at age 23 to a state-operated hospital for the mentally retarded and has been continually institutionalized from that time.

A review of institutional records from shortly after Mr. A’s admission to the state hospital revealed an array of maladaptive behavior, exclusively motivated by cigarette smoking. This included aggression towards others to gain cigarettes, “frenzied anxiety” and self-injury if not able to attain cigarettes and theft to gain cigarettes. He was described by direct support professionals to be, “constantly begging for cigarettes” and “smoking whenever he had the chance.” Cigarette smoking was a consistent theme in his behavioral repertoire until age 67, when three small myocardial infarctions in a span of several months prompted the team managing his care to eliminate his ability to smoke. At the age of 73, Mr. A was discovered to have inoperable adenocarcinoma of the right lung.

A review of the records from his many years of institutional living did not reveal any attempts at smoking cessation (despite always having had a legal guardian). Conversely, cigarettes were utilized as reinforcement when he was able to complete tasks of daily living. Hence, he was conditioned, through behavior modification interventions, that smoking was a reward, furthering the notion that cigarettes were an important part of his life. His level of cognitive ability may have precluded realistic education about the health risks of smoking, but a record review did not indicate any attempts at education or other creative attempts to provide alternative emotional rewards.

The Case of Mr. S

Mr. S is a 36-year-old Caucasian man. He is considered to have mental retardation in the mild range. Review of records indicated that he was born prematurely and had Rubella at age 14 months. There were modest developmental delays in early childhood and behavior from that point on was described as hyperactive. It was also reported that he had poor impulse control, which resulted in acts of aggression and self-injury when frustrated. Delinquent behavior in his midteenage years, including aggression towards his parents, necessitated placement in a community-based residential program at age 18. This evolved into involuntary commitment to a state-operated residential facility due to continued aggression, self-injury, and running away. He has resided in a state-operated institution since age 20.

Mr. S’ behavioral regression while still in the community was largely due to his discovery of cigarettes and inability to regulate smoking. This pattern has continued since his institutionalization. A routine of cigarette smoking currently governs both appropriate and maladaptive behavior. If he is not able to smoke at a desired time, he is prone to act out towards
others or himself. There are many documented incidents of aggression toward others and he recently had surgery to correct a detached retina, which was a result of self-injurious behavior. He does not currently appear to have smoking-related medical conditions.

There have been many efforts made to educate Mr. S regarding the risks of smoking and to demonstrate to him the relationship between his inappropriate behavior and cigarette smoking. This began around age 22, when he agreed to attempt a smoking cessation program. Intense anxiety without cigarettes (despite having nicotine replacement) caused him to revoke his participation in the intervention after one day. His treatment team felt that, despite his self-guardianship, Mr. S was not able to fully appreciate the long-term health ramifications of smoking. He was adjudicated incompetent, and an advocacy service agreed to provide guardianship. To date, smoking cessation has not been thought to be part of the guardianship process and smoking cessation has not been a priority among Mr. S’ other problems.

**DISCUSSION**

Only a few authors have attempted to examine the ethical issues involved in the use of tobacco products by persons with MR/DD. Smoking within this population immediately presents several apparent paradoxes. Most authors agree that competent persons with MR/DD have a right to smoke if they make this decision in an informed manner. Most authors also agree that competent individuals with MR/DD who do not smoke and direct support professionals who are not smokers, have a right to be free of second-hand smoke-related risks and should be able to choose to live and/or work in a smoke-free environment. Others have noted that persons with MR/DD who are not competent must be protected from the risks of smoking, in that they are unable to protect themselves and need the system (caregivers, family, guardians, professionals, etc.) to provide this protection. This type of protection has generally been available to persons living in institutional settings, such that most institutional settings have provided safeguards by removing cigarettes from the environment, providing secluded areas for smokers (residents and employees) and limited access to other tobacco products (including smoked cigarette butts). In non-institutional settings, the issue becomes more difficult. In smaller residential settings, and particularly in individual homes or apartments, it is not as easy to mandate smoking policies, often more difficult logistically to provide truly smoke-free environments for some but not for others and perhaps impossible to monitor smoking practices.

Another (and perhaps larger) issue surrounds the notion of competence and the validity of this concept as it addresses the use of tobacco products by persons with MR/DD. In spite of a concerted effort on the part of government and the health care industry to warn of the dangers of smoking, nearly 25% of the general population continues to smoke. Whether this is a response to successful advertising--marketing by the tobacco industry, a volitional choice by the smoker himself, or a result of addiction to nicotine, is currently being debated in a variety of court rooms and lawsuits. One might predict, as has been suggested by others, that persons with MR/DD would be more susceptible to the advertising campaigns of the tobacco companies which promote smoking, and which associate smoking with a normal, mature, or glamorous lifestyle. This might even be more of an issue for persons with mild or borderline disability, as in the case of Mr. S. Individuals functioning within this domain may be more prone to recognize the discrepancy of their own lifestyle limitations to those in the general population and be more motivated to engage in behavior such as smoking, that will procure a position in such a desired lifestyle. Additionally, the societal view of smoking when Mr. A was an adult smoker (who did not yet exhibit the symptoms of smoking-related illness), was that of fashionable and glamorous.

Following this logic, it may be that even competent individuals with MR/DD may not be competent to make a truly informed choice in the area of smoking. Should direct support systems (family, agency staff, guardians, professionals) take a more active educational and/or restrictive stance toward smoking by otherwise competent adults with MR/DD, in order to counteract the combination of advertising and the presence of physiological addiction, which promote smoking?

The concept of consent, and competence to consent, has legal, and ethical, as well as clinical implications. Applebaum and Roth have presented a four-tier approach to determining a person’s capacity to consent, which begins with the ability to communicate choice (most basic level). The second level is the ability to understand
factual information, followed by the appreciation of the situation and its consequence (third level). The final level of consent is the capacity to rationally weigh the risks and benefits of a proposed treatment (the most cognitively complex). Several authors have attempted to study consent methodology as it applies to persons with MR/DD. Cea and Fisher examined 90 adults (30 with mild MR/DD, 30 with moderate MR/DD, and 30 without MR/DD), presented several clinical vignettes and then rated their decision-making capacity on Applebaum's four levels of consent capacity. The authors found that 86% of those with mild and 45% of those with moderate MR/DD could communicate a choice (lowest level) and 85% of those with mild MR/DD could demonstrate a partial or full understanding of factual information (second level). However, much lower percentages of adults with mild or moderate MR/DD were able to understand the third and fourth levels of consent capacity. The authors' instrument, the Assessment of Consent Capacity-Treatment (ACC-T), appeared to demonstrate that some persons with mild/moderate MR/DD have the ability to provide adequate consent to standard low risk health-related treatments. Mr. S (identified previously), despite having only mild developmental disability, generally demonstrates only the most basic level of communicating choice utilizing Applebaum and Roth's criteria. He can clearly indicate that he would rather smoke than not smoke. However, he does not have the consistent ability to understand factual information in any area, including smoking. For example, in a recent examination of his cognitive ability, Mr. S was unable to identify the number of days in a full week. Mr. S also has little or no ability to appreciate a situation and its consequences. In the same examination, he was not able to identify why a car needed an engine, or why people at times needed to be put in jails. Mr. A, in retrospectively examining his smoking behavior, seemingly demonstrated the ability to make a choice to smoke. However, in examining his current status, choice making does not seem to be a clear and consistent ability in other areas of his life. This would put Mr. A at a consent capacity less than that of Mr. S. Beyond a marginal ability to demonstrate level one consent, Mr. A currently does not understand factual information, cannot appreciate a situation or its consequences, nor rationally weigh risks and benefits of his actions. It is certainly feasible to assume that he did not possess these skills when he did smoke. This raises the question of whether Mr. A, who never received any therapy or intervention aimed at smoking-cessation before his cancer diagnosis, would otherwise be facing such a devastating illness.

In non-health-related areas, some authors have viewed the choice to smoke by persons with MR/DD as similar to other lifestyle choices, such as drinking alcohol, maintaining a healthy diet/exercise regimen, and sexual behavior. Kennedy and Niederbuhl have identified “consensus criteria” for sexual consent capacity in persons with MR/DD. In their study, psychologists identified those intellectual and behavioral areas they thought necessary to be able to engage in consensual sexual behavior. The authors identified several core areas as necessary for consent capacity, including basic sexual knowledge, knowledge of the consequences of sexual behavior, and abilities related to self-protection. Perhaps similar “consent capacity” criteria could be established for persons with MR/DD with regard to smoking behavior. To our knowledge, no such “consent capacity” has been previously suggested for smoking or other use of tobacco products.

Although similar in concept, a major difference between sexual behavior and smoking would appear to be the addiction component of tobacco use. Smoking and use of tobacco products appear to be fundamentally different from other life-style choices, such as the decision to engage in sexual behavior. Howe notes that the apparently rational appearance of patients with substance use disorders may be misleading. He notes that direct support professionals for those individuals should presume that those who are truly addicted might pursue their addiction above all else, even in the face of having apparent consent capacity in other areas. This would appear to apply to individuals with MR/DD who are technically competent, but addicted to nicotine. This addiction, aided by the active promotion of cigarette use as “profitogenic” for the tobacco companies, may render even apparently competent persons unable to freely “choose” to continue smoking. From this perspective, activities that individuals, or agencies (or tobacco companies) engage in that encourage smoking in those without consent capacity should be viewed as inappropriate and/or unethical. Until such “consent capacity” for smoking is established, perhaps the most pragmatic and beneficent approach is to continue to allow competent...
persons with MR/DD the right to choose to smoke, but make continued efforts to provide education regarding health-related risks in order to inform their choice. Such an approach has been suggested by Burtnet. At the same time, protection must be afforded to the incompetent individual with MR/DD, to protect him or her from the risks of smoking and tobacco use, either by the individual himself, and/or from second-hand smoke or other tobacco products. This should be true whether the tobacco exposure is from peers with MR/DD, or direct support professionals who are smokers.

**CONCLUSIONS**

At this time, there is no established guideline for determining the capacity of individuals with MR/DD to make informed choices regarding smoking or other use of tobacco products. Persons with developmental disability continue to smoke, as in the case of Mr. S, and continue to suffer from smoking-related illness, as in the case of Mr. A. Consent capacity guidelines, as they relate to smoking by persons with developmental disability, need to be established. Until guidelines to determine smoking consent capacity are objectified and accepted, the assessment of smoking potential for those with developmental disability should proceed as follows:

1. Persons with MR/DD who are incompetent should not be permitted to smoke, use other tobacco products, or be exposed to second-hand smoke, regardless of their residential or vocational circumstance.

2. In order to smoke, persons with developmental disability should be required to demonstrate the highest level of consent capacity, that is, they should be able to communicate a choice to smoke, understand factual information regarding the risks of smoking, appreciate the situation and its consequences, and be able to weigh the risks with a rational manipulation of the information available. This should be accomplished utilizing smoking education programs, modified for the developmental level of the individual, but not minimizing or misrepresenting the risks of smoking. If, after such education is provided, an individual is able to consent at the highest level, he or she should be permitted to smoke.

3. Those not able to demonstrate the highest level of consent capacity, should ultimately not be permitted to smoke. Individuals with developmental disability not demonstrating the highest level of consent capacity who currently smoke, should not be permitted to continue smoking. The case of Mr. S would likely be an example of this circumstance. Given that Mr. S has been exposed to numerous efforts to educate him about the risks of smoking, and would likely not be able to demonstrate the highest level of consent capacity specifically related to smoking, he should not be permitted to smoke. Development of smoking cessation programs specifically oriented to developmental level, assistance with addiction (utilizing nicotine replacement programs), and the use of psychotropic medications would all be integral components in helping to transition persons from smoking to non-smoking. Such an approach would serve to interrupt the current pattern of allowing individuals who are not able to consent to begin or continue smoking. Their choice to smoke is often ultimately a choice to die of smoking-related illness.

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**CORRESPONDENCE:** Stephen L. Ruedrich, M.D., Associate Professor of Psychiatry, Case Western Reserve University School of Medicine, MetroHealth Medical Center, 2500 MetroHealth Drive, Cleveland, OH 44109; tel.: 216-778-4626; fax: 216-778-8412; email: sruedrich@metrohealth.org.