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Discussing drinking with paediatric patients with neurodegenerative conditions raises a wide range of dilemmas

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It is illegal to sell alcohol to individuals under 18 years old in Italy, but quite common for older adolescents to consume alcohol with friends (1). Adolescents share an experience reserved for adults as they enter a different phase of life together and most survive without damage, or addiction, but rare experiences of acute alcoholic intoxication. Drinking alcohol can be a social ritual that differs from searching for extreme emotions, binge drinking or partying at a rave.

Paediatricians know that their patients should avoid alcohol, especially younger ones, due to the increased vulnerability of the developing brain to its neurotoxic effects. There is strong evidence that drinking at an early age can cause brain damage. Studies have showed a dose-related effect, accelerated frontal cortical grey matter (2), disrupted spatial working memory (3), increased anxiety in binge drinkers and early vascular damage (4).

However, adolescent mental wellbeing is also related to positive social interactions and strong, protective peers, including inexpensive risk-seeking behaviours that explore new possibilities and gain autonomy.

So what happens when you see a 17-year-old boy, accompanied by his parents, who asks if he can have a beer with his friends at a party? In most cases, beer is clearly unhealthy and it is a legal decision. But what if he has muscular spinal atrophy type 2, lives in a high-tech mobile chair, with non-invasive ventilation and a gastrostomy, can talk and interact and has a very active social life? What should the physician do?

What about the law, which prohibits alcohol before 18 and imposes strict penalties on vendors? What about the justice of allowing a disabled adolescent to break the law to try and compensate for his congenital defect? And what about his parents and the friends drinking with him?

Alcohol is toxic for adolescents, and the law is the law, but what about the biological difference between a patient the day before and after their 18th birthday? Breaking the law should not be taken lightly, particularly for teenagers, but strict laws could even represent injustice. Four motivations for alcohol use have been theoretically identified: social and recreational, coping with negative life events, compulsive use and drug effects (5).

Any ethical debate should consider moral agents. These include principlism, which is based on respect for autonomy, nonmaleficence, beneficence and justice. This helps people to reach decisions, and answer their

own questions, having considered the best options. We tried to apply principlism to this case. This may offer food for thought especially considering the different lifestyles of adolescents with neuromuscular disease.

Autonomy comes from the Greek words for self and law. The Principle of Respect of Autonomy, also known as the Principle of Human Dignity, states that physicians must respect the decisions patients make about their own lives. An adolescent is exposed to so many peer experiences. Our patient has fully intact cognitive functioning and capacity of judgement. It is hard to assess such capacities in a progressive disease like his, as it affects alpha-motoneurons and the psychological ability to evaluate the best options.

However, as the 1998 Nobel Prize winner for literature José Saramago wrote in his *Ensaio sobre a Cegueira (Essay on Blindness)* 'not all individuals react in the same way to the same stressor'. In addition, the Italian philosopher Pico della Mirandola's 1486 oration on *De dignitate hominis (About human dignity)* stated that: 'The human being is placed at the centre of the Universe in order to evaluate all the phenomena up to 360° and to decide consequently'. Because our actions are influenced by our environment, and vice-versa, an adolescent with limited access to leisure activities can idealise the recreational value of alcohol and see it as an easy way to socialise with friends. One study reported that children with chronic disabilities used social media as a coping strategy and increased and decreased that use when they felt more or less incapacitated. Could we say the same for moderate and occasional alcohol consumption? Perhaps our adolescent has other reasons for drinking, like relief from his condition? When this happens does Principlism clash with the complex issue of autonomy? (7).

What if the adolescent and his parents disagree? Parental opinions are essential to therapeutic alliances, but may be somewhat prejudicial, due to their caregiving role and their desire to control when alcohol is available. Finally, the physician's autonomy should be considered, along with their desire not to break the law for something they do not agree with.

The principles of beneficence and nonmaleficence in the Hippocratic Oath state that physicians must balance the benefits against the risks and costs, while avoiding harm. It could be argued that telling the patient it is fine to have a beer enables him to behave, at least partly, like a healthy peer and enjoy his social life. But that may cause alcohol-related damage (8) and even risk dependence. This would definitely worsen his condition, because patients with neurodegenerative conditions face greater possible damage because of a weaker tone and a greater impact on their respiratory drive. Acute intoxication also significantly risks life-threatening accidental injuries or the need for emergency treatment, which is higher in fragile neuromuscular patients.

Important practical issues should be explored. What kind of alcohol, how much, who should provide it and where? Drinking at home is very different from being out with friends. A cautious step-wise approach could be to have some drops of beer or wine placed in his mouth at the next family party, see how this goes and eventually do the same with friends. His parents should be fully aware of how reliable his friends are.

Does asking for privacy away from parents indicate he is adopting a greater risk-taking attitude? Perhaps allowing the patient to have beer in a controlled, safe setting would do him good, by not taking away his adolescent privileges?

Lastly, the Principle of Justice states that we must provide others with what they are owed or deserve. We could argue that justice is allowing the patient to make an informed choice or that the decision should be driven by the most imperative necessity. Physicians consider the psychological effects of diseases, which may vary over time and are specific to when questions are asked. Even patients with severe chronic illnesses live to fulfil their dreams and aims, not follow doctors' instructions.

There is no easy answer to this complex question and various issues should be considered. Even if the parents agree with their son drinking, the physician should tell the patient they cannot condone the activity for legal and health reasons. At the same time, the physician should state that they understand the motivation behind the request and encourage the adolescent to consider key issues when deciding, such as whether they are doing it just to fit in and whether they understand that their medical condition makes drinking more dangerous.

Finally, the risks and benefits for physicians who endorse risk-taking behaviour in a vulnerable minor should be considered. The ongoing relationships with the child and his family play a pivotal role and physicians should only discuss such issues in a spirit of mutual knowledge and trust with the patients and the family.

This situation has many grey areas and difficulties, but an aware, informed adolescent should be helped to live life as fully as possible. As the English poet W E Henley wrote in his poem 1875 poem *Invictus*: '*I am the master of my fate, I am the captain of my soul*'. Perhaps the adolescent in this case is like a captain, who has the occasional beer while steering his own course.

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CONFLICTS OF INTEREST

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References:

1. Arria AM, Caldeira KM, Moshkovich O, Bugbee BA, Vincent KB, O'Grady KE. Providing alcohol to underage youth: the view from young adulthood. *Alcohol Clin Exp Res*. 2014;38(6):1790-1798.
2. Pfefferbaum A, Kwon D, Brumback T, Thompson WK, Cummins K, Tapert SF, et al, (2018) Altered Brain Developmental Trajectories in Adolescents After Initiating Drinking. *The American journal of psychiatry*, 175(4), 370–380.
3. Galaj E, Kipp BT, Floresco SB, Savage LM. Persistent Alterations of Accumbal Cholinergic Interneurons and Cognitive Dysfunction after Adolescent Intermittent Ethanol Exposure. *Neuroscience*. 2019;404:153-164.
4. Charakida M, Georgiopoulos G, Dangardt F, Chiesa ST, Hughes AD, Rapala A, *et al*, Early vascular damage from smoking and alcohol in teenage years: the ALSPAC study. *Eur Heart J*. 2019 Jan 21;40(4):345-353.
5. Patric, ME, Schulenberg JE, O'Malley PM, Maggs JL, Kloska DD, Johnston LD, *et al*, Age-related changes in reasons for using alcohol and marijuana from ages 18 to 30 in a national sample. *Psychology of addictive behaviors:journal of the Society of Psychologists in Addictive Behaviors*, 25(2), 330–339.
6. De Nardi L, Trombetta A, Ghirardo S, Genovese MRL, Barbi E, Taucar V, Adolescents with chronic disease and social media: a cross-sectional study. *Arch Dis Child*. 2020 Aug;105(8):744-748.
7. Davis RB. The principlism debate: a critical overview. *J Med Philos*. 1995 Feb;20(1):85-105.
8. Simon L, Jolley SE, Molina PE. Alcoholic Myopathy: Pathophysiologic Mechanisms and Clinical Implications. *Alcohol Res*. 2017;38(2):207-217.