When the Disabled Become Isolated: The Story of Snowflake

Dallas Ducar

Bioethics, Snowflake, MCS

INTRODUCTION

On the outskirts of a small town called Snowflake, just 150 miles northeast of Phoenix, Arizona lies a small community suffering from a disease known as Multiple Chemical Sensitivity (MCS). Those with MCS suffer from migraines, fatigue, rashes, and other incapacitating symptoms which they believe to be due to chemical sensitivities. Perfumes, detergent, smoke, and many other artificial chemicals are thought to be the cause of such sensitivities.

ANALYSIS

People with MCS arrive from around the nation, generally due to overexposure to multiple chemicals, pollen, or other environmental pollutants. Many who have chemical sensitivities also have electromagnetic sensitivities and have fled from what is known as "electropollution."¹

The population of this community attempts to build with "safe" materials such as ceramic tiles rather than carpeting, which can capture certain odors. The electrical sensitivity has causes some members of the community to build their houses without installing electricity. However, many remain worried as a new resident or company could build with "unsafe" materials, which may force many to leave the place they call home, once more.

The residents of Snowflake have generally suffered from more than MCS. The needs of many of the residents are strict, they require very certain "safe" products and generally cannot enter into larger communities. Therefore, most of the people with MCS are unable to work and many of their spouses end up leaving.

However, this community of three dozen households is a promised land for many of the arrivals. Many claim to have been suffering for years and are simply looking for refuge. There are reports of many others who call weekly, asking for availabilities, generally met with disappointment and grief.

The problem is that most scientific studies have been unable to show any strong connection between exposure to these chemicals and the symptoms being reported. Moreover, the American Medical Association does not recognize the MCS as chemically-caused. Blinded clinical trials have shown those with MCS react as often and as strongly to placebos.² Fundamentally, many doctors still disagree about the exact etiology, claiming that the symptoms may be physiological, psychological, or both.

Regardless of the etiology, these are human beings claiming to have severe, disabling symptoms which result in a complete uprooting of their lifestyle.

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The unrecognition of MCS by the larger community poses a more general question. Some residents do not do not receive disability benefits as MCS is not fully recognized. Is it just for the state to not offer assistance to the sufferers of MCS? Even for the doctors who doubt the etiology of MCS, shouldn't more research be invested to ensure these people are helped?

This is most likely the first time you have heard about MCS. However, MCS is a name all too familiar to the residents of Snowflake, Arizona. Who will speak out for this small town when a new gas station decides to move in? Who tells the new family building with "unsafe" materials that they cannot move to Snowflake?

It is quite possible that without proper representation, the residents of Snowflake are inadvertently isolating themselves. However, MCS is unique as it inhibits sufferers from entering any large area where public policy decisions would be made in the first place. MCS can result in isolation, thereby resulting in less advocacy for those afflicted.

When considering the rights of those afflicted with MCS it is also important to understand what the government may owe to these people. When considering whether to recognize a paraplegic as qualifying for disability benefits, one does not look primarily to the cause, so why is this the case for sufferers of MCS?

CONCLUSION

While some may not take their disability seriously, they do. Cases such as this create impetus to ask what classifies as a disability, why it is a disability, and what should be done, if anything, to change this mentality.

The residents of Snowflake are real people with real voices. Even if the pain may be psychologically induced, does this make the suffering and disability any less real?

¹ http://www.eiwellspring.org/Arizona/SnowflakeCommunity.htm

² J. Das-Munshi, G. J. Rubin, S. Wessely, Multiple chemical sensitivities: A systematic review of provocation studies, *Journal of Allergy and Clinical Immunology*, 118, pp.1257-1264 (2006)