An Inclusive Approach to Addiction Care—Helping the Helpers

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People living with substance use disorders (SUDs) live within families and embedded relationships that can be critical sources of resilience and practical support. These concerned significant others are positioned to provide endogenous support (originating from within), such as parents, siblings, partners, caregivers, or close friends. Assistance may include love, friendship, and emotional support, or it may include instrumental support, such as transportation and childcare, emergency assistance in the event of an overdose, financial support, and/or housing.

People living with SUDs also interact with exogenous supporters (originating from the outside): social workers, case managers, peer navigators, and others. These exogenous supporters have relationships fostered through formal organizations or social entities. When members of the research or policy communities cite evidence-based interventions, they typically refer to interventions that focus on such exogenous supports.

Careful attention to such exogenous supports is essential to support effective interventions and practices—and to curb interventions that are harmful or punitive. The corresponding tendency of much existing research is to emphasize users of drugs and their decisions to engage and interact with different types of exogenous staff, supporters, or caregivers. This focus on exogenous supports easily neglects the reality that users of drugs, like all people, thrive within environments of social support. Research and policy communities pay less systematic attention to endogenous supporters of people who are active users of substances or in recovery. These communities also pay less systematic attention to hybrid models that combine exogenous and endogenous supports to reduce drug-related harms.

To be effective, present, and supportive, endogenous helpers also need support. These include linkage services to help loved ones obtain pertinent information and secure entry to effective treatment and harm-reduction services and legal and housing assistance. The evidence-based literature is surprisingly meager regarding how best to assist actual or potential endogenous supporters in these efforts.

Family and social network ties can become bidirectional sources of pain and vulnerability. Family supporters may feel inadequate in their ability to be useful or effective. Helping may impose or trigger secondary traumas, particularly if supporters themselves are burdened by current or past histories of substance use or mental illness. Supporters bear witness to a loved one's pain and experience realistic fears that their loved one may be arrested, lose housing or employment, or experience serious injury or overdose.

Such experiences can generate burnout and secondary trauma. Supporters may also experience financial harms that arise from lost work time or from the need to provide economic support to their loved one. Supporters are sometimes exposed to harmful behaviors such as illegal drug possession or sale in the family home, placing other household members at legal risk or eviction risk. A loved one might make unauthorized use of a supporter’s credit card, given the financial imperatives that can accompany SUD. In some situations, supporters themselves might lose housing, partnership, or other resources if they back out of the helping role or face pressures from other institutions to provide support when this expectation is not in their best interest.

Policy makers understandably view supporting relationships through a victim-support dyad, in which the person living with an SUD is the primary person harmed by their disorder, with less attention paid to the capacities, needs, and agency of their endogenous supporters. This perspective must be broadened to accommodate more complicated realities, for example, when the supporter...
is a child, parent, or partner who has experienced harm resulting from substance misuse by a loved one. Supporters of people living with an SUD typically face greater stigma—and receive fewer community and service supports—than do others, for example, caregivers for loved ones living with intellectual disabilities.²

All supporters require effective and sustainable practical backing to address their needs, particularly when supporters themselves experience accompanying hardships or harms. Supporter ties can also impose burdens on people living with SUD who require such assistance.¹ Supporters may lack knowledge of—or be understandably ambivalent about—harm-reduction interventions they associate with continued substance use. Endogenous supporters may pressure loved ones into abstinence-based rather than evidence-based interventions such as medications for opioid use disorder, which some mistakenly perceive as substituting one drug for another.³

An inclusive approach must engage these realities of human connectedness.⁴ Systematic reviews suggest that family and partner social network interventions can help loved ones initiate and maintain engagement with effective treatment interventions.⁵⁻⁷ Yet, with important exceptions, strategies for “helping the helpers” are understudied. Too little is known about how supporters’ activities are best leveraged to improve treatment outcomes and reduce drug-related harms. (Though beyond the scope of this essay, too little is also known about how best to design interventions or practices to support the human needs of exogenous supporters, whose social proximity to people who use drugs, commitment, and cultural competence may arise from their own lived experience of similar needs and related vulnerabilities.)

In contrast to the burgeoning literature on family caregiving and Medicaid disability waiver services,⁸ few addiction studies specifically explore supporters’ physical and mental health. Greater research attention should focus on supporters’ well-being as legitimate primary outcomes, not merely as mediating pathways to ensure beneficial outcomes for others. Overemphasis on exogenous services neglects the social reality that the most intensive and lasting supports typically come from endogenous helpers, who may themselves require economic support and emotional support.

More subtly, this research gap hinders efforts to understand ways the legitimate interests of people who use drugs can diverge from those of their immediate supporters—and, thus, to understand ways these divergent interests might be negotiated. For example, a person who injects drugs should be encouraged to use syringe exchange and naloxone distribution services. Supporters must be self-aware of how their own challenges and the wider society’s biases may lead them to embrace misguided approaches⁵—for example, pressuring loved ones to pursue abstinence-oriented treatments unlikely to reduce drug-related harms or help those in recovery. Harm-reduction proponents must be correspondingly aware that interventions such as syringe exchange do not, by themselves, address many harms experienced by endogenous supporters.

From a political perspective, supporters’ lived experience at times makes them a visible political constituency—one that brings both beneficial and harmful frames to addiction policy and clinical interventions. Thus, supporters have important opportunities to embrace improved access to effective practices and treatment.⁸ Also untapped and understudied are opportunities for hybrid support systems or interventions, ways that combined efforts of endogenous and exogenous supporters may create more sustainable arrangements to support both users of drugs and their most immediate supporters. We have seen such developments in care in the context of elder care and disabilities, less so in substance use. Such attention may generate new evidence concerning myriad problems that can arise, such as how to reduce exposures to criminal legal liability or eviction due to an individual’s drug use, how to use behavioral contracts that protect supporters themselves against threats to their well-being, and how best to provide crisis management services to supporters when their loved one is overdosing or refuses treatments.

Millions of people in the US experience some level of substance use or SUDs. Most manage these challenges in ways that do not harm others or themselves. When honoring the dignity and
human rights of all people, we should also acknowledge the shadows that SUDs can cast over surrounding lives. People who experience SUDs deserve support and help. So do their supporters, helpers, and caregivers. Helping the helpers should be a high priority in both an inclusive approach and within revised drug policies to promote the well-being of all people affected by drug use.

ARTICLE INFORMATION
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