The Transition from the Child-Adolescent to Adult Systems of Care for Eating Disorders:

Challenges and opportunities for patients, parents and treatment providers

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Eating disorders often begin in adolescence. Many adolescents, however, will require treatment beyond adolescence and will need to transfer from the adolescent system of care to the adult system. The two systems have much in common, typically offering a multidisciplinary approach to the medical, nutritional and psychological aspects of eating disorders, and a stepped level approach to care, with outpatient, day treatment or inpatient services offered depending on the severity of the illness. However, significant differences between the two systems may present challenges, as well as new opportunities, for individuals, their families and treatment providers, as patients make the transition from one system to the other.

Levels of motivation and responsibility

One significant difference is the level of motivation and responsibility to seek and engage in treatment that is required of the patient. For adolescents, assessment and treatment is often initiated by their parents. While most adolescents are generally deemed to be as competent as adults to consent to treatment, in practice, parents, in their role as caregivers and custodians, have both a responsibility to seek treatment for their ill child and the leverage to induce a reluctant child to participate in treatment. Although resistance to treatment is recognized as a common element in eating disorders for both adolescents and adults, the adolescent system is more oriented to treating "reluctant customers" than the adult system. Concerns about the impact of the eating disorder on normal growth and future health, and evidence that adolescents have better outcomes than adults, create a sense of urgency among treatment providers to intervene. Accordingly, the adolescent system takes a proactive stance towards providing treatment. It both welcomes and enlists parents as treatment allies to ensure that adolescents with little or no motivation for recovery receive treatment. Should parents be incapable of ensuring that necessary treatment is provided, the treatment team may enlist the assistance of child protection agencies to intervene in the case of adolescents under sixteen.

In contrast, patients in the adult system of care are afforded considerably more autonomy in choosing whether to engage in treatment and to determine which level of care they are willing to participate in. It is only when a patient's health is severely compromised that the imposition of treatment against the patient's will is even considered, and then only after careful review of the therapeutic, ethical and legal implications of treating without consent versus failing to treat. Accordingly, patients transferring to the adult system must have at least a minimal level of motivation to pursue continued treatment. Should they refuse treatment, they are unlikely to be pursued actively by the treatment team and typically receive the message that they are welcome to return when ready to engage in treatment. Acquiring greater autonomy to choose whether or not to participate in treatment may affect individuals' levels of motivation in different ways. Those with low motivation for recovery may choose to opt out of treatment. Their parents may in turn experience a sense of hopelessness and/or helplessness at no longer being able to get

treatment for their young adult child who has rejected treatment, but who remains seriously ill. Others, who may have been struggling with control and autonomy issues, may react positively when there is less coercion from parents or the treatment team, and may at last be able to commit to working toward recovery on their own behalf. Individuals who are ambivalent about recovery may miss the loss of structure and support as decisions about continuing in treatment are left increasingly up to them.

Family involvement

A second important difference between the two systems is the degree of family involvement. Studies comparing individual therapy with family therapy suggest that for children and adolescents under eighteen, family therapy was superior in producing positive outcomes, while for adults, individual therapy was superior. Accordingly, in the adolescent system, family involvement is typically viewed as central to the individual's recovery, with individual and group interventions provided as adjunct therapy. Most adolescent eating disorder programs are family oriented and parents are considered essential treatment allies whose involvement is not only encouraged but may be mandatory. Family issues that affect the adolescent's symptoms, and the impact of the eating disorder on the family, receive attention and are often a central focus in therapy. Information about the patient's health status is typically shared with parents and they may be enlisted to monitor their child's food intake and/or other eating disorder symptoms.

In contrast, in the adult system, the central focus of treatment is the individual, who is deemed responsible for her/his recovery. While family oriented interventions may be recommended and made available, they are often viewed as adjunct therapies. Information about the patient's health status is not shared with parents without the patient's consent, unless specific conditions governing the breaking of confidentiality (e.g. when patients are at risk for harming themselves or others) are present. Thus, as patients move from the adolescent system to the adult system, parents' involvement in their treatment may become more peripheral, and information available to parents about their child may be reduced significantly.

Parental responses to changed treatment responsibilities

For parents used to being actively involved in their child's treatment, the transition from the adolescent system to the adult system may leave them feeling sidelined and powerless. They may feel their role as concerned parents is not recognized adequately by the adult system. Particularly when older adolescents or young adults continue to live in their parents' home, parents may feel they have the right to be informed about their child's illness and treatment, and may feel frustrated at being shut out. Some parents, on the other hand, may have found the level of involvement required by the adolescent system onerous for a variety of personal or logistical reasons, or they may have become increasingly frustrated by limited or slow progress towards recovery. For these parents, reduced involvement in their child's treatment may be a welcome relief. They may perceive the transition as an appropriate time to relinquish responsibility for recovery to their child, and feel ready to accept a more peripheral supportive role.

Adolescent responses to changed treatment contexts

For adolescents, the shift in balance from a heavier focus on family involvement to a greater focus on individually oriented interventions may also be experienced positively or negatively. Adolescents who perceived family involvement as intrusive may be relieved to finally be able to

obtain treatment independently. Increased control over information shared with their families may allow them to reveal and resolve issues they may have been reluctant to address when they had less assurance about confidentiality. For adolescents whose illness may have served the function of eliciting desired involvement from parents they perceived as too distant, or who may not feel ready to assume more independence, reduced family involvement in their treatment may be experienced as abandonment, and generate feelings of loss.

A third difference between the two systems is the wider age range served by the adult system, compared to the adolescent system. While younger adolescents clearly differ in significant ways from older adolescents, they have more in common than, for example, a nineteen year old college student living at home and a thirty-five year old, married, working mother. Adolescents moving from the adolescent system to the adult system may find themselves in group-oriented treatment programs with older adults whose life experiences and concerns are outside the range of their experience and possibly disturbing. Depending on the age-range of other patients in the program at the time of transition, the individual making the transition may experience a greater or lesser degree of comfort, identification with other patients, and sense of belonging in the adult system.

Moving on

Finally, the transition from one system to the other will require that patients, parents and the treatment team work through issues of termination. These may include feelings of loss or abandonment, anxiety related to leaving a familiar treatment team and starting with a new, unfamiliar one, concerns about establishing trust with a new treatment team, and/or frustration or anger about unmet needs. There may be disappointment that positive, productive therapy relationships cannot be continued or relief that difficult or unproductive therapy relationships are coming to an end. Patients, parents and the treatment team need to be aware that positive or negative feelings and expectations about treatment that were developed in the adolescent system may be carried over into the adult system and affect both motivation for treatment and the quality of new therapy relationships. Despite these issues, for many patients, the transition may allow a fresh start and new opportunities for recovery and personal growth.

Suggestions for managing the transition

For patients

- Become informed about the adult system.
- Use transition as an opportunity to re-evaluate motivation for recovery.
- Re-evaluate what worked and what didn't.
- Keep an open mind.
- Let your parents know how they can continue to support you.

For parents

- Become informed about the adult system.
- Take part in parent education or support groups if available.
- Ask you child how you can continue to support her/him.
- Encourage your child to assume more responsibility for treatment and recovery.
- Be prepared to give your child more autonomy.

For treatment providers

- Become informed about the system your patients are going to, or coming from.
- Establish linkages with the other system to facilitate smooth transitions.
- Assess the impact of previous treatment experiences on motivation for change and receptiveness to treatment.
- Discuss concerns about transition with patients and parents.
- Allow sufficient time to work through termination issues.

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