Managing the Parents

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Introduction

It is obvious but important: Birth initiates parenting, rather abruptly, with all of the inherent mysteries of who and what this baby will grow to become. For any parent preparation for this moment will include a mix of hope, excitement, fear, uncertainty, deep thought and delusion. Nothing quite prepares a parent for that amazing, precipitous, emotional and humbling event. However, a newborn with any major anomaly naturally enshrouds new parents in heightened anxiety and even greater uncertainty about the future. Parenting such a child impacts the child's health and development throughout young life. Thus, managing the parents throughout the child's life becomes an important part of clinical strategy; this is no less apparent during the clinical transition from adolescence to adulthood. There are no recipes, no real guidelines, for managing parents during this period. To be sure, parent management is part of the art of practicing medicine. The research literature is nearly nonexistent; the few studies available generally describe only parent perceptions of transitional care, parent-child relations or the overall transition processes. There are, however, important insights to be offered about managing parents of adolescents affected by urological anomalies.

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Parents will evolve their strategies slowly during the child's early years. The approach to adolescence presents a new frontier for parents, a reality often requiring new rules—or at the least an adjustment of old approaches. In the clinical setting an adolescent is a new patient to the clinic, designing management strategies for both child and parent may be difficult and time-consuming. Managing the parents of any affected adolescent often requires more focused direction than managing the parents of an affected prepubertal child and may benefit from an interdisciplinary team for several reasons. First, parents are likely to differ (father from mother) in emotional and behavioral reaction to clinical and behavioral realities, care, or problems [1]—this is not necessarily new. Second, adolescents gradually become more active participants in their own healthcare and development—this is new and presents an additional dimension to the differences (already mentioned) between parents. Third, parents attend to their child, to their child's needs, sometimes to the exclusion of their own needs—especially when they experience simultaneous competition for their time and emotional commitment from the needs and demands of others within or outside of the family. Fourth, typical parents feel that they know their child. But younger children do not verbally express or even comprehend their self interest well, while the adolescent has achieved far greater expressive and receptive verbal skills. Still, the adolescent typically verbalizes only a small portion of their inner thoughts and may not even direct such verbalizing to their parents. Managing the parents, then, becomes a broad-based clinical challenge.

Naturally, parents have a strong influence over the relationship with their child, and indeed, over all family relationships. Thus, abusive or neglectful parents can impede or otherwise damage their child's development and health. With more typical parents, however, "good enough" parents or with parents and child who are a "good enough fit" for each other, the child is likely to develop and adapt well enough. In fact, each child has to adapt to nonfamily social situations and milieux, parental involvement notwithstanding. In other words, children learn to adapt and sometimes to maladapt to their social situations and also to their parents. Away from their parents, adolescents' behavioral and emotional states, their activity and reactivity, tend to reflect more programmatic interactions of their genetics, epigenetics, and environmental or external experiences.

Such interactions are, for the most part, continual just as they are difficult to tease apart, one from the other. High levels of child-reactivity, and especially negative reactivity, correlate to a higher risk for the development of anxiety disorders—in later life. This is true for children as well as for adolescents and parents [2]. From the perspective of parent management goals, however, it is important to realize that behavioral research increasingly demonstrates that children (like their parents) have temperament-associated emotional reactivity that has strong genetic correlations. For example, in a very large study of twins from two different continents, differences between negative, neutral, or positive reactivity correlated more strongly with genetic than with environmental (including parent-input) differences [3].

This is not to say that parents are not important. Many of the developing child's early social situations and much of their emotional development occur within the context of the family. More to the point, when children are young, parents possess

and wield the executive functions of the family—that is, those critical social functions that control attention, organizational and planning skills, working memory, emotional regulation, and other critical cognitive social functions. Child and adolescent brains progressively develop these executive functioning skills over more than two decades. Studies of these developmental processes are well represented in research literature.

Unfortunately, only limited studies and scarce data are available to reflect such adolescent development in those with chronic urological conditions. Nonetheless, their experiences of repeated surgery, anesthetics, and multiple hospitalizations in infancy and later childhood likely impact and may render negative vulnerabilities for these cognitive developmental processes. Parents, moreover, have no experience or innate social supports in dealing with children with such chronic maladies. This combination of voids limits our ability to standardize parent management and education for urological disorders even as parental anxiety is typically increasing over time [4].

A discussion of family therapy, systems therapy, or other behavioral interventions—for father, mother, adolescent, or the family unit—is beyond the scope of this paper. But these clinical realities become increasingly complex from a management standpoint, as the child moves into adolescence, and demand a team approach. To adapt to a progressing adolescent development in the face of urological anomalies, and with little help from experience or their own social milieu, parents do need assistance. Add to the mix a set of complex parents, and the clinical approach can become at times almost overwhelming.

Therefore, active and appropriate management of the parents while encouraging their participation demands a multidisciplinary team. The team requires varying members depending on the clinical status of the patient and on the social status and emotional and cognitive states of the parents. Adolescent and adult mental health care professionals who are likely to enhance the clinical team should include: (1) a clinical social worker experienced in family and social and ecological needs of adolescents with complex urological disorders; (2) a psychologist skilled in assessing cognitive as well as emotional variables in parents and in adolescents; and (3) a psychiatrist skilled in treating family as well as adolescent psychopathology. These professionals may often meet or work as a subunit of the team. Each can have a clinically significant impact depending on clinical variables at a given time.

Clearly in the adolescent with urological disorders, the development of the parental role in care will be complex. To be able to assess, treat, and support the parents and the family, the urologist and the team need to master and apply several skills:

1. Engaging and educating the parents as clinical and social situations evolve;
2. Helping parents manage boundaries between their adolescent and themselves;
3. Recognizing when and how parents should be included, excluded, or simply encouraged to retreat to the background from patient discussions and physical examinations;

4. Maximizing the privacy and ultimately the confidentiality of the adolescent and the adolescent in transition to adulthood.

These should be regarded as "moving targets" both in terms of adolescent as well as of parental development and require flexibility from the team.

Engaging and Educating the Parents Through the Transition

Information is critical to parents, as it will be to the adolescent. In the information age clinical education requires accuracy, appropriate knowledge and understanding if the urologist is to help direct parents toward their future roles in parenting. As with most people, parents learn best with repetition of important points over time accompanied by written educational materials. For accuracy and for reference basic condition-specific developmental processes can be outlined and provided early and intermittently in printed form. A printed summary every year or so, specific to the adolescent, keeps parents up-to-date and can include insights about likely future clinical directions. The urologist can help parents compare and contrast the clinical educational materials to information or misinformation gleaned from the Internet.

Nothing, however, is likely to be as useful as the formal encounter between the urological team and the parents (or the patients) who are perplexed. First, the team must educate the parents about the importance of the clinical transition itself—the "why" and the "how" of transition. Second, the urologist and other team members will need to re-engage parents periodically when clinical complications arise, as well as when adolescent needs (as opposed to those in childhood) and desires begin to prevail. Being familiar with the social and emotional states of the parents over time is quite useful, especially when the urologist must discuss new or troubling clinical information. The team may have to manage the overly involved parent—the so-called hovering or "helicopter" parent. Managing the hovering parent early and regularly can help prevent emotional enmeshment between parent and child and, later, between parent and adolescent. The team can gradually redirect hovering behaviors towards a more useful, involved healthcare focus.

A major part of the team, the clinical social worker can direct parents to appropriate groups for support, including local or regional groups or national or international support group websites. Managing parental expectations is also important in managing adolescent health care. The social worker along with support groups can augment appropriate parental management. However, managing expectations of the parents depends on their cultural perspective, cognitive function, educational background, emotional state and how they adapt to those parameters [5]. Having a rough understanding of the parents' gross executive functioning skills (including reading level) will enhance clinical communication as well as the adolescent's healthcare and transition. Educating the parents about the adolescent's likely developmental potential and vulnerabilities enhances managing the parents and therefore managing the adolescent. After all, it is the parents who must understand and master the

clinical care responsibilities and requirements, such as clean intermittent catheterization, bladder washouts, and so forth. It will be up to the parents to re-enforce the urologist's teaching of these responsibilities to the adolescent. Generally, the team's psychologist can best assess parents' (and the adolescent's) cognitive and learning potentials and how to address the clinical implications. (An example of an excellent screening tool would be the BRIEF, or Behavior Rating Inventory of Executive Function [6]. Available from the PAR website, there is a version for parents, teachers, and the patient, with an excellent explanatory guide book with definitions of the executive functions.)

Parents will likely recognize some of their adolescent's developmental vulnerabilities. However, they are not likely to be sophisticated about the implications of urinary incontinence, genital anomalies or disease-chronicity likely to be associated with adolescent anxieties—or the realities—about potential sexual function, reproduction, romantic relationships and even peer relationships. These developmental vulnerabilities are atypical if compared to vulnerabilities in adolescents with chronic but non-urological disorders and will be mostly foreign to the parents. Parents are also likely to be ill-prepared for boundary issues inherent to these developing vulnerabilities. The psychiatrist can provide appropriate assessment and treatment for developing adolescent or parent psychopathology, or appropriate referral if desired.

Helping Parents Manage Boundaries with Their Adolescent

Boundary issues are common between most parents and adolescents. While there is a growing behavioral literature debunking any major parental influence on developing personality, temperament, cognition, and even outcomes, boundary issues between parents and the affected adolescent often impact short-term behaviors and emotions and sometimes long-term parent-child relationships. Boundary issues inherent to most chronic adolescent urological disorders often create stresses and even long-term conflict that may impact adolescent autonomy and health care. Therefore, helping parents manage boundaries is important to the entire team.

Although specific details of clinical strategies will relate to the urologist's approach to parents of the adolescent with a specific urological condition, certain parent management strategies need to be emphasized:

- Begin early—establish clinical "rules" as part of the educational processes for the parents
- Re-enforce these early rules by repetition as the child develops into adolescence
- Modify the rules as the adolescent grows and develops, i.e., as needs transform
- Establish which rules are strict and which can be adapted to or by the parents
- Distinguish between the specific needs of adolescent autonomy and the variability of parenting styles as the adolescent develops—and as the parent develops.

Adolescents are inherently sexual. Chronic urological disorders influence and impact sexuality. As might be expected, many affected adolescents questioned their sexual potential well before they entered puberty; in fact, anxieties about future sexual function often begin during school-age [7]. Therefore, the early education of the parents should be formatted to include sex education of the child during development specific to the underlying urological disorder and well before adolescence begins.

A trusted professional, the urologist is also “an outsider”: the intimacy of a discussion about sexuality is therefore diffused and in some ways sublimated when conducted between the patient and urologist. Therefore, it is important early in the management of parents to establish the rules and roles for the urologist and for the parents in terms of adolescent discussions and adolescent education. The urologist will educate the parents early in the child’s development about sexual potential and sexual function. As the child nears adolescence and especially after puberty begins, the urologist should be the mainstay of the sex education of the adolescent patient. Printed tables or flowcharts outlining relative roles can be especially useful when provided early in parents’ education and again several times as the child matures (see Table 6.1). The urologist and the parents can refer to such a flowchart repeatedly, as necessary.

When parents are asked to step out, or at least to retreat to the background, the adolescent can begin to comprehend the nature and importance of privacy and the confidentiality of the subject matter. Once a set of rules for a given set of parents or for a given adolescent are established, they should be largely maintained unless clinical exigencies (such as pregnancy or illness) intervene. Reifying the relative roles of educator begins to create an almost formal if initially unrecognized separation between urologist and parents, at least in terms of the adolescent’s sexuality, while augmenting the clinical relationship between urologist and adolescent. This is the initial transition for the adolescent and for the parents—when the adolescent begins to look to the urologist for critical information rather than to the parents. This process is often the beginning of establishing the ultimate autonomy of the emerging adult.

Our own REACH Clinic at the Oklahoma Children’s Hospital, University of Oklahoma Health Sciences Center in Oklahoma City (Oklahoma, USA) is an example of a model of an adolescent- transition clinic. With a focus on adolescents with neurogenic bladders, the clinic provides interdisciplinary healthcare, local and regional support group access, and direct participation in community social and sporting groups for the adolescents and their families—with healthcare providers often participating. It also provides materials explaining available participatory

Table 6.1 Example of a simple flowchart, here providing suggestions for who the educator should be, and during which ages of the patient

Child’s age	Educator
Birth to 7–8 years old	Parents, with urologist providing needed background information
9–11 years	Parents, with urologist present
12–14 years	Urologist, parents not present but informed
15 years–emerging adulthood	Urologist, parents not present, not informed

community programs, national and international support groups, and website information for participation. These approaches focus on ultimate adolescent independence but also on providing healthcare settings as well as social access that encourage a sense of comfort for parents and for adolescents alike.

Recognizing When and How Parents Should Be Excluded

The process of moving the adolescent from dependence gradually to autonomy, therefore, is initiated with the parents well before adolescence even begins. However, a specific set of clinical rules may be modified based on parents' temperament and disposition as well as on an adolescent's own cognitive and personality realities. For example, an adolescent with myelomeningocele, hydrocephalus, and a ventriculoperitoneal shunt may have reduced cognitive and executive functions when compared to an adolescent with bladder exstrophy—establishing rules allows the urologist to work with the parents while working with the adolescent. In establishing such rules, it is important to recognize that parenting is in a sense "an institution" of Human Nature—with legal and ethical aspects for the parents of protecting, nurturing, decision-making, and so on [8].

There is an art to the manipulation of the clinical situation such that the parents gradually and adequately transfer their control to the adolescent under the scrutiny of the team. To be sure, legal and ethical aspects also envelop the clinical team. In other words, boundaries exist for all parties involved. Decision-making must evolve into a mixed process between parents and adolescent. The ultimate aim, clearly, is independence as possible for these adolescents when they reach adulthood.

Along this line, relevant and material themes for the adolescent include more than simply having discussions in private. Indeed, the physical examination can provide an additional avenue for educating the parents about child and adolescent development with increasing stress on patient privacy. For the majority of parents and for social and cultural appropriateness, when the child is young the parents should not only be present, but it is probably best if at least one parent is near to the child during physical examinations. For school-age children clinical situations tend to be emotional and high anxiety even with an otherwise calm child. Anxious situations are not conducive to learning or listening. Therefore, parents should be present and encouraged to take notes or be provided with printed materials. As the child nears adolescence, however, emotional and anxious reactions of the adolescent or between adolescent and parents may be problematic and are likely to intensify: heightened anxiety may relate at least partly to the presence of the parents and the fabric of the family dynamics. It is often best, therefore, to usher the parents out or at least to the background.

Adolescents generally do best with parental distance or absence. This is especially true when the substantive matters involve mastery and self-care. Adolescents generally learn better and listen better when they are alone with an educating member of the team. Once the adolescent is alone any uncomfortable family dynamics are absent, anxiety diminishes, emotions tend to stabilize. The adolescent can be

encouraged to take notes. Notetaking will be novel, to the young adolescent, in the clinical setting, as will autonomy. These are learned traits. Educating the adolescent begins simply and progresses through the more complex. This is the best approach for the parents as well. The adolescent, of course, can inform the parents about anything discussed. At the first few meetings it may be sensible to offer (to the adolescent) a further, joint conversation with the parent to support wider communication. They may or may not consent to this but it (importantly) gives them the choice.

Therefore, depending on the child's age and level of development, the parents should be close but not necessarily present in the exam room. As the child moves into adolescence and truly begins to grasp an understanding of their diagnosis, treatment and their own responsibilities, the urologist can ask the parents to step out and can provide the printed materials to the adolescent, then separately to the parents. The process of moving the parents towards a recognition of the magnitude of necessary autonomy is usually gradual. Again, printed materials that outline this transformation are most useful, especially if the materials are initially provided before the child begins adolescence. Discussions that necessarily require both parties can be modified accordingly at any time, with major modifications in the case of an adolescent with significant cognitive or executive function deficiencies, who may not be able to achieve much independence.

However, some adolescents need or feel they need more parenting than others. An adolescent who requests parental presence may indeed be signifying their own specific autonomy. Here again the team approach is valuable in helping guide the adolescent and the parents, as well as the team itself, in an appropriate even if idiosyncratic clinical approach.

Maximizing the Confidentiality of the Adolescent Through the Parents

By emphasizing the need to move towards adolescent autonomy, the urological team encourages and teaches the importance of privacy. Managing the parents requires educating them about necessary privacy issues for their adolescent; educating them about privacy encourages adolescent confidentiality. In other words, early education about the importance of privacy becomes a springboard to later education about the importance of confidentiality.

Privacy is an issue the child will likely grasp fairly early in school-age years, as anxieties arise and gradually intensify about the possibility of discovery by peers—discovery of urinary incontinence, genital abnormalities, or a stoma. This risk or the fear of discovery can lead the family toward secrecy for parents and for the child. In managing parents, preventing or eliminating secrecy by instruction on the nature of privacy when the child is young can help reduce stressful life events or anxieties both within the family dynamics and within the child's external social milieux. Eventually, this sense of privacy can transform into a recognition of the need for confidentiality for the adolescent. Gently but firmly helping parents to step out when necessary patient discussions or queries are likely to impinge on patient

emotions helps the early adolescent grasp the potential of their impending independence as well. A growing sense of independence enhances learning as it empowers and augments adolescent development.

A parent management approach that fosters adolescent independence can easily begin with the childhood physical exam. Such an early strategy is likely to be successful long-term. Young adolescents often do not mind if their parents are present during physical examinations. To prepare both parties for privacy issues, having the parents step out or at least to step into the background when the genital exam is to begin can be initiated in late prepubescence, well before adolescence begins. In this way, the urologist begins to prepare parents and patient for the gradual transition regarding privacy, especially in terms of the young adolescent's burgeoning if somewhat vulnerable sexuality. This preparation also augments the boundary rules established earlier in the parent-urologist relationship. By mid adolescence, the parents can be encouraged to step out for the entire physical examination if this is okay with the adolescent. This approach emphasizes privacy for the adolescent but begins the process of establishing confidentiality.

Privacy is necessary for the child's protection within any social milieu. Confidentiality allows the adolescent similar protection—the sense of the sexual self relates not only to one's romantic relationships but also to peer relationships—while allowing and encouraging the adolescent to explore questions of social and sexual intimacy. Exploring these themes, adolescents can deal with their own urological realities relating to sexual function, fertility, relationships, and peer interactions. Initially, some of these topics can be broached with the parents present. Most of these questions should be encouraged after the parents step out, however. Developing this sense of confidentiality allows protection within the adolescent's social circle, then, as well as the broader external environment.

Confidentiality along with self-confidence of the adolescent can be engendered within the context of increasing the sense of privacy, integrity, and autonomy initially within the family. Parents can and should be informed early in their adolescent's development of the nature of present and likely future discussions between the child or adolescent and urologist. As the adolescent develops further, however, the parents might not be included, even after the fact—although the adolescent of course can tell them everything. Parents' understanding of this unfolding process is part of the urologist's engaging and educating the parents as it simultaneously prepares them (and the adolescent) for the developmental attainment of adolescent confidentiality.

Conclusion

The practice of adolescent urology includes sensitive issues. Sexual matters are indeed private; complicated urinary functions can be embarrassing. Parents will understand this clinical emphasis on privacy. However, matters of urinary incontinence, intermittent serious illness, recurrent stone disease, urgent hospital admissions or reoperations also require privacy and confidentiality. Peers may not honor

or understand the adolescent's need for privacy. The adolescent may feel or may fear a need to explain to friends or peers. Adolescent sensitivity may not be obvious to the parents, who may be in need of emotional and social support themselves. Parent management processes, then, often require an emphasis on the privacy of the family, beginning when the child is an infant. Early emphasis on family privacy can then evolve towards a re-emphasis on the privacy of the child in particular, a privacy with respect to the family initially but ultimately leading to a sense of overall confidentiality. The privacy of the young adolescent, then, merges with the need for confidentiality as part of the increasing autonomy of the emerging adult.

Parents are likely always to be a part of their adolescent's developing and adult life. Managing the parents while treating the adolescent enhances this development while minimizing the risk of exacerbation or exploitation of vulnerabilities—of both adolescent and parents. By focusing on the processes, the urologist sponsors and emphasizes a gradually diminishing course of parental involvement, albeit specific to a given adolescent's needs and grasp of the clinical demands and realities. This sense of autonomy empowers integrity and confidentiality for adolescent as well as for parental development and transition. Healthy parental development encourages healthy adolescent development—this is an important two-way process.

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