Pediatric-to-Adult Transfer of Care in Patients With Pancreas Disease: Recommendations for Care and Research Opportunities

Cheryl E. Gariepy, MD[1], Luis F. Lara, MD[2], Jeffrey J. Easler, MD[3], Ala Shaikhkhalil, MD[1] and Aliye Uc, MD[4]

Young adults who have experienced recurrent acute pancreatitis and chronic pancreatitis as children or adolescents are vulnerable to poor follow-up and disease management during the transfer from the pediatric to adult healthcare system. Although formalized transition programs for young adults have been developed and described for other disease conditions, no such program has been described for young adults with pancreatic disease. This document is the first expert opinion outlining the important aspects of a transitional care and transfer program tailored to youth with recurrent acute and chronic pancreatitis. We emphasize the unique needs of these patients as they transfer to adult health care and the need for further research. The goal of improved transitional care and transfer is to enhance the services provided to adolescents/young adults with pancreatic disease in both healthcare settings and improve continuity of follow-up care.

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INTRODUCTION

Over 500,000 individuals with chronic medical conditions move from pediatric-to-adult (P2A) medical care yearly (1). The P2A transfer typically occurs during late adolescence to early adulthood, a time with many challenges and expectations that may lead to low prioritization of health care. Chronically ill young adults are more likely to suffer the negative consequences of a poorly planned P2A transfer process compared with healthy young adults (2–4). Transitional care is the provision of resources to the medical, psychosocial, and educational/vocational needs of adolescents as they transition from parent-supervised and managed care to independent, patient-centered care. P2A transition can occur without transfer, but transfer in the absence of transition is often unsuccessful. The ideal P2A transfer of care follows a purposeful and planned transition with the goal of continuity of care to optimize long-term health outcomes (5).

Pancreatitis is an emerging entity in the pediatric population (6–8). Chronic pancreatitis (CP) may affect young children but often begins in early adolescence and can result in lifelong chronic pain, exocrine pancreatic insufficiency (EPI), diabetes mellitus (DM), and potentially pancreatic cancer (7–11). Six core disease-neutral elements of transition have been identified by GOT TRANSITION, a program of the National Alliance to Advance Adolescent Health, which culminate with integration of the youth into the adult healthcare system with an understanding and acceptance of their illness and adherence with medical care (12).

Currently, there are no recommendations for P2A transitional care or transfer in pancreatic disease. This report is based on expert opinion and consensus outlining the important aspects of CP in pediatrics and adults and a P2A transfer program tailored to the youth with recurrent acute pancreatitis (RAP) or CP with the aim to enhance the transfer process, stimulate discussions on this topic, and call for further research.

SPECIAL DIAGNOSTIC ISSUES IN YOUNG ADULTS

CP is a progressive inflammatory disorder, resulting in destruction of the organ, for which there are multiple risk factors, including genetic, metabolic, anatomical, and environmental, often occurring in combination (13–16). In children and young adults, the most common risk factors for CP are genetic and anatomic while environmental modifiers (i.e., alcohol and smoking) play a larger role in older adults (8,17–24).

Because ideal management requires identifying risk factors early and implementing strategies to prevent or delay progression and complication, genetic testing with appropriate counseling is recommended in children and young adults with RAP or CP (16). Most commercially available tests include *cationic trypsinogen (PRSS1)*, *cystic fibrosis transmembrane generator (CFTR)*, *serine protease inhibitor Kazal type 1 (SPINK1)*, and *chymotrypsin-C (CTRC)*, which increase the risk of early-onset CP, and where disease phenotype may depend on the types and number of variants, but new variants continue to be discovered (6,8,11,16,25–32). The results can lead to disease-altering, life-changing interventions: The diagnosis of cystic fibrosis (CF) or a CFTR-related disorder would lead to the assessment of disease in other organ systems and open the door to therapy with a CFTR modulator while the identification of a high-risk PRSS1 pathogenic variant would lead to increased surveillance for complications and early consideration of

[1]Nationwide Children's Hospital and The Ohio State University College of Medicine, Columbus, Ohio, USA; [2]The Ohio State University Wexner Medical Center, Columbus, Ohio, USA; [3]Indiana University Health, Indiana University School of Medicine, Indianapolis, Indiana, USA; [4]University of Iowa Stead Family Children's Hospital, Iowa City, Iowa, USA. **Correspondence:** Cheryl E. Gariepy. E-mail: Cheryl.Gariepy@NationwideChildrens.org.
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treatment options such as total pancreatectomy and islet autotransplantation (TPIAT) (15,26,33–39). Table 1 summarizes pancreatitis susceptibility gene variants.

SPECIAL MANAGEMENT CONCERNS IN YOUNG ADULTS

Nutrition, diabetes mellitus, and exocrine pancreatic insufficiency

Individuals with RAP and CP have unique nutrition-related needs. Registered dietitian nutritionists (RDNs) are an integral part of the multidisciplinary team, particularly during the adolescents' critical period of growth and development, when nutrition-related deficits can have long-term effects and affect functional outcomes and quality of life (QOL). In 2018, the North American Society of Pediatric Gastroenterology, Hepatology, and Nutrition (NASPGHAN) Pancreas Committee and European Society of Pediatric Gastroenterology, Hepatology, and Nutrition (ESPGHAN) Cystic Fibrosis/Pancreas Working Group developed the first set of expert recommendations on nutritional assessment and management of children with RAP and CP (40). In 2020, the American College of Gastroenterology (ACG) also highlighted multidisciplinary management of CP in their clinical care guidelines for adults (15). In addition, the NASPGHAN Pancreas Committee published a set of guidelines in 2020 for the medical management of children with CP that includes a section on nutrition management (41). All of these documents emphasize the paucity of nutrition-focused studies in RAP and CP.

Current pediatric and adult recommendations include a regular diet (as opposed to low-fat); regular assessment of weight, height, and body mass index; and monitoring fat-soluble vitamin levels (40,41). In adults, monitoring for mineral and trace element deficiencies is recommended (15). These recommendations are based on studies in older adults with CP, most of whom were male and many of whom continued to consume alcohol and smoke tobacco (42,43). Whether these recommendations are appropriate for adolescents and young adults with CP, many of whom are female, is not clear (8).

Table 1. Genetic risk factors associated with recurrent acute or chronic pancreatitis (1)

Gene symbol	Inheritance pattern	Clinical significance
PRSS1	Complex, low penetrance	CP, early-onset CP, rapid progression to CP
CFTR	AR	Many mutations; variable presentation, rule out CF
SPINK1	AR	2% of population; homozygous with severe disease
CTRC	AD	CP, early-onset CP
CPA1	Complex, low penetrance	Early-onset CP
CEL	AR	CP, MODY

AD, autosomal dominant; AR, autosomal recessive; *CEL*, carboxylester lipase; *CFTR*, cystic fibrosis transmembrane generator; CP, chronic pancreatitis; *CPA1*, carboxypeptidase A1; *CTRC*, chymotrypsin-C; MODY, maturity-onset diabetes of the young; *PRSS1*, cationic trypsinogen; *SPINK1*, serine protease inhibitor Kazal type I.
[Ref 15.]

Both the pediatric and adult guidelines recommend screening for EPI and DM (specifically type 3c, T3cDM) yearly and starting individuals with EPI on pancreatic enzyme replacement therapy (PERT) with the guidance of an RDN (44–47). Failure to diagnose and treat young individuals with EPI and DM can result in growth delay or failure. Children with DM are managed in conjunction with an endocrinologist and an RDN (48,49). For adults with DM, referral to an endocrinologist is usually at the discretion of primary care physicians. This difference in practice should be discussed with the patient because it may be disquieting for the young adult to no longer see an endocrinologist.

Bone health

Bone health has age-based implications in pancreatic disease. Adolescence is a critical time for accruing bone mass, thus creating an opportunity to prevent long-term poor bone health (50). Sparse data in children with CP suggest that up to 20% may have low bone mineral density (51). Osteopathy is present in up to 65% of adults with CP, may be independent of underlying EPI, and can be associated with deficits in muscle mass, hand grip, and increased risk of fracture (52,53). The assessment of bone mineral density using dual-energy x-ray absorptiometry (DEXA) scans in those with CP who also have malnutrition, vitamin D deficiency, or history of fractures is recommended in children where opportunistic identification of a fat mass on DEXA screening may also correlate with malnutrition and poorer clinical outcomes (40). In adults, a baseline DEXA scan should be obtained at the first visit and repeated at least every 3 years (44).

Social support

Young adults with any chronic illness will face challenges in higher education; independent living; acquisition of health habits related to exercise, alcohol, tobacco, and recreational drug use; and developing sexuality. Medical systems can be particularly challenging for young adults who may not be highly motivated to engage in the process. Young adults have higher rates of uninsurance and inpatient utilization, particularly minorities and those with low income (54). Social workers are an integral part of the multidisciplinary team and transitional care team because they can help the patient and family navigate the transfer of care and work with medical providers to help the patient develop emergency plans for disease exacerbations.

Young individuals with RAP and CP can face skepticism from employers and educators because of the "invisible" nature of their disability. They may also be hesitant to disclose their illness, request reasonable accommodations in school/work settings, and have concerns of being penalized for missing class or work because of illness-related absences (55). This may be particularly true with RAP and CP because these diagnoses may be stigmatizing in adult care where alcohol abuse is more likely to be suspected and an opioid requirement may be confused with opioid addiction or abuse. Transitional care should include education about disability rights in addition to support to build the patient's skills and confidence to advocate for themselves (56).

Pain management

Chronic abdominal pain is associated with a reduced health-related QOL, poor sleep, and academic and social functioning (57–61). The need for frequent medical visits and interventions can have a bidirectional, potentially compounding effect on chronic pain. An interdisciplinary, personalized, and tiered approach is

recommended to achieve best outcomes. This approach should begin under pediatric care and continue after transfer to the adult healthcare setting.

Adolescents with behavioral and mental health disorders are at increased risk for disengagement from the healthcare system, particularly in the challenging P2A transfer process (62). A collaborative interdisciplinary approach to pain management with robust involvement of mental health professionals is recognized as crucial to reducing healthcare utilization, improving mental health by promoting coping skills and reducing maladaptive behavior (58,63–65). Psychological diagnoses need to be documented and followed up because they can exacerbate stressors associated with transfer (58,63–65). Early intervention may alter the complex chronic pain syndrome in adults with CP that has local, central, and somatic components (66).

Opioids are frequently used in the treatment of pain in pediatric and adult CP (67,68). Prescribing rates of opioids in adolescents and young adults increased rapidly through the 1990s and remains high (69,70). Reliance on opioid use is concerning given their lack of effective long-term pain control and their association with worse functional outcomes and increased mortality (58,69–72). Non-narcotic management with medication (gabapentin, nonsteroidal anti-inflammatories, amitriptyline), hypnosis, comfort therapies neurostimulation, and cognitive behavioral therapy are recommended approaches if these services are available, although their effectiveness has not been well studied (73–75). The gastroenterologist caring for young adults should use nonopioid pain control as much as possible. Referral to a comprehensive pain management program, if available, is recommended.

Disease modifiers

Strong evidence supports an independent effect of smoking in promotion of acute and CP and pancreatic cancer (76). Eighty percent of people who use tobacco start before adulthood, so prevention activities should start in the pediatric setting and be continued on transfer (77). The role of e-cigarettes/e-vaporizers on pancreatic disease is unknown, but this is a gateway to traditional combustible tobacco product use and should be avoided (78,79).

The risk of developing pancreatitis increases with increased consumption of alcohol, and early alcohol use is a significant risk factor for later alcohol abuse. By the age of 15 years, approximately 30% of teens in the United States have had at least 1 drink, and people aged 12–20 years drink 11% of all alcohol consumed (80). Lifelong abstinence is strongly recommended. Alcohol abstinence education generally has little success, but it may be more successful in those with RAP and CP because patients and families are usually anxious for interventions to reduce pain and prevent disease progression.

Recommendations

- Children and young adults should be tested for genetic variants associated with pancreatic disease. This may need to be repeated as new genetic variants are identified.
- Genetic counseling should be offered to young adults to enhance understanding of the disease, including inheritance.
- Referral to a center with expertise in pancreatic disease is recommended for patients with a pathogenic genetic variant.
- Nutrition monitoring should be performed routinely in patients with pancreatic disease. Management should be individualized and include a registered dietician nutritionist when possible.
- Patients with CP should be screened yearly for DM and EPI.
- Individuals with low bone density should be evaluated for nutritional deficiencies.
- Patients with recurrent acute pancreatitis and CP would be screened for vitamin, mineral, and trace element deficiencies as per society guidelines.
- Patients with frequent episodic or chronic pain should be screened for depression and referred to specialists as indicated.
- Patients with recurrent acute pancreatitis and CP and significant pain should be referred to a comprehensive pain management specialist if available.
- Children, adolescents, and young adults with pancreatic disease should be targeted for tobacco and alcohol abstinence education.

TRANSITION TRACKING, READINESS ASSESSMENTS, AND PLANNING

Transition and transfer readiness assessments should begin with youth parents/caregivers at least 2 years before the anticipated transfer. General disease-neutral assessment tools are available, such as TRAQ, at www.gottransition.org (81). Items typically covered in a transition readiness assessment include (i) managing medications and appointments, (ii) awareness of healthcare history, (iii) participating in visits/communicating directly with providers, and (iv) development of independent life skills (82). The objective is to standardize assessment and implementation of transition activities so that knowledge and skill gaps are identified early and P2A transfer is not delayed. These assessments should occur every 6 months and progress should be recorded. Patients of at least 18 years who have met transition milestones, have healthcare insurance, and are in a relatively stable social situation should transfer to the adult healthcare system.

Planning transfer

Pediatric providers need to assist the patient in identifying an appropriate adult healthcare provider. Adult pancreas disease specialists are more likely to be found in academic medical centers or large practices. National Pancreas Foundation Pancreatitis Centers undergo a rigorous credentialing process are a resource for pediatric and adult providers (83). The young adult should be responsible for contacting the new provider and scheduling an appointment and then informing the pediatric center to establish contact and start the transfer of information.

Young adults with RAP or CP are likely to experience episodic worsening of pain. It is very important that there be no confusion regarding which provider they should contact at each point in the transfer process. We recommend a series of exit visits between the patient, their caregiver(s), and pediatric provider specialists during the 6–12 months before transfer (5). Core providers such as the patient's pediatric pancreatologist, nurse, dietician, social worker, and pain management specialist and psychologist, if applicable, should be included. The focus of these meetings are several fold: (i) Ensure that the patient is able to independently consolidate and communicate their history and current therapeutic plan; (ii) identify any active pancreatic disease symptoms or complications that are likely to carry through and require further diagnostic testing, therapeutic adjustments, or surveillance; (iii) delineate which provider should be contacted for urgent help and when that will change; (iv) ensure that an adult pancreas disease care provider has been

identified and contacted before exit; and (v) allow for adequate time to communicate with the patient's adult provider during the transfer.

Although adolescents and young adults may remain on their parent's insurance until the age of 26 years, young adults need to realize the agency in the management of their chronic disease, including maintaining health insurance, and avoid gaps in access. A clinical summary should be developed by the pediatric team and provided to the patient and the adult healthcare provider, preferably electronically. We recently queried members of the adult working group for CP of the Consortium for the Study of Chronic Pancreatitis, Diabetes, and Pancreatic Cancer to grade elements of a pancreas P2A medical summary that would be most useful (84). Based on this information (data not shown), we propose a transfer-of-care document in Supplementary Figure 1. The patient should also request release of all medical information to the new provider, preferably through the electronic health record (EHR).

TRANSFER TO THE ADULT HEALTHCARE SYSTEM

Recommendations

- Transfer planning and transitional care should begin before the age of 16 years.
- Transitional care should include educational materials as well as readiness assessments, disease assessments, and assessments of social and insurance stability.
- Transfer readiness includes being at least 18 years; meeting transition milestones; and having stable disease, living situation, and healthcare insurance.
- When the patient is assessed as ready to transfer, a transfer summary document should be prepared by the pediatric care team, reviewed with the patient/family, and provided to the adult provider before the first visit with the new provider.
- Communication between the pediatric and adult healthcare teams should occur in person or virtually and include pain specialists, psychologists, and nutritionists when applicable.

Table 2. Pancreatic disease pediatric-to-adult transfer-of-care checklist for patients 18 years and older

Before transfer
• Obtain and review the transition summary document from the pediatric pancreas provider.
• Obtain and review medical records.
• Record contact information of the pediatric providers.
• Determine who needs to participate in "warm" handoff and set up in-person or virtual meeting.
Handoff
• Participate in "warm" handoff.
• Medication review with indications and alternatives that have been tried.
• Discuss pain management needs.
• Determine whether additional referrals are needed. Make sure the patient has a primary care provider and get contact information.
• Medication review with indications and alternatives that have been tried.
• Discuss tobacco use, alcohol use, and contraception, if appropriate.
• Ask patient to sign consent and additional release of information forms, if appropriate.
• Review insurance coverage, copays, and other administrative forms.
• Schedule a multidisciplinary new patient visit.
After transfer of care to adult healthcare provider
• Establish a multidisciplinary new patient visit.
• Confirm that a last clinic visit with the pediatric provider has occurred.
• Make certain that the patient has access to medical records.
• Provide detailed contact information including after-hours contact information.
• Reassess transition readiness.
• Medication reconciliation with review and adjustment of doses, side effects, and contraindications.
• Determine the need to refer to a primary care physician, dietitian, endocrinologist, etc.
• Discuss and consider referral to genetic counseling.
• Discuss and document opioid use and sign opioid contract.
• Discuss and reinforce abstinence from tobacco smoking and alcohol.
• Use recommended care guidelines and order imaging/testing accordingly.
• Provide educational material and links.
• Agree upon the best emergency department and inpatient facility(s) to seek care if urgently needed.
• Schedule return visit at a short interval.

Most commonly, a youth with pancreatic disease will be transferring from a pediatric specialist (or several pediatric specialists) to a general adult gastroenterologist or an adult pancreas center. An attempt should be made for the pediatric and adult specialists to meet in person or virtually. Medical records should be reviewed together, and paper and/or electronic records including the transfer summary document should be provided (see Supplementary Figure 1, Supplementary Digital Content 1, http://links.lww.com/AJG/C611). Methods to store and share this document electronically, preferably through the EHR, should be developed (85). If possible, pediatric and adult care coordinators, case managers, social workers, dietitians, and others should participate in the "warm handoff" in the patient's presence. Consent and confidentiality forms can be discussed and signed. Ideally, a transfer care coordinator would coordinate the process, although this expertise is usually not available (12).

Because of the COVID-19 pandemic, the use of telemedicine platforms has gained traction and will likely remain an option for some individuals to access care. Although an in-person handoff of care is ideal, teleconsultation is appropriate and more realistically achievable. Furthermore, telemedicine technologies can serve as a resource for local gastroenterologists for guidance and consultation with the patient's pancreas specialists (86).

Having a smooth transfer and continuous comprehensive pain management through P2A transfer may enhance a young adult's path toward independence and improved QOL as well as reduce resource utilization. Consequently, patients who need an adult multidisciplinary pain management specialist should establish care early in the process. With good handoff communication, the adult gastroenterologist can identify other referrals that need to be made during the transfer and thus minimize gaps in care. An independent handoff between the patient's pediatric and adult pain management teams is recommended. An opioid contract should be reviewed and signed if these medications are part of their pain management strategy. The psychological impact of the disease may also require regular visits with a psychologist and/or psychiatrist (71,87). Table 2 is an example checklist for P2A transfer for individuals with RAP or CP.

INTEGRATION INTO ADULT HEALTH CARE

Ample time should be allowed for the first visit of a transferring youth in the adult healthcare system, which should include members of the patient's care team, including nursing and administrative staff, and the managing gastroenterologist. Multiple tools and guidelines are available to help grade the severity of CP and outline diagnostic and therapeutic strategies for the management of the young patient who is

Table 3. Pancreatic disease P2A initial assessment and subsequent care in the adult healthcare setting

Category	Guideline-based care recommendation (1–4)	P2A transfer considerations
Tobacco and alcohol cessation counseling	Screen for alcohol and tobacco exposure. Counsel patient regarding strict avoidance of alcohol and tobacco. Arrange smoking cessation interventions.	Screen for alcohol and tobacco exposures. Reinforce absolute abstinence. Discuss cessation strategies with the primary care physician.
Abdominal pain	Preferentially use nonopioid pain medications. For patients with moderate-to-severe pain, enlist the services of a pain management specialist. Consider antioxidant therapy and celiac plexus block for select patients. Referral to interventional endoscopy, pancreatic surgery, and a TPAIT center can be considered.	A separate handoff may be required if the patient has a pediatric pain specialist. Consider referral to an adult pain specialist as part of the transfer-of-care process. Obtain updated cross-sectional imaging. Consider interventional endoscopy and surgical options when indicated (e.g., pancreatic duct obstruction and RAP).
Malnutrition and EPI	Screen for evidence of malnutrition and EPI. Initial investigations should include noninvasive pancreatic function testing (s-MRCP, qualitative fecal fat, and FE-1). Manage EPI with weight and symptom-directed PERT; adjust as appropriate. Screen patients for EPI-associated nutrition and mineral/trace element deficiencies every year: B12, zinc, magnesium, and fat-soluble vitamin deficiencies. Baseline DEXA screening and repeat in patients with long-standing CP and evidence of EPI and/or malnutrition. In patients with EPI and/or malnutrition, an RDN should be a member of the adult care team.	Screen for EPI with FE-1. Have the patient evaluated by RDN. Ensure appropriate PERT dosing if appropriate. Check B12, zinc, magnesium, and fat-soluble vitamin levels. Obtain DEXA.
Pancreatic endocrine insufficiency (diabetes mellitus)	Screen patients with RAP and CP for diabetes with a FPG and HbA1c at the time of diagnosis and yearly after diagnosis.	Check fasting glucose and HgbA1C In patients with diabetes, an adult endocrinologist should be a member of the care team.

CP, chronic pancreatitis; DEXA, dual-energy x-ray absorptiometry; EPI, exocrine pancreatic insufficiency; ERCP, endoscopic retrograde cholangiopancreatography; FE-1, fecal elastase; FPG, fasting plasma glucose; HbA1c, hemoglobin A1C; P2A, pediatric to adult; PERT, pancreatic enzyme replacement therapy; RAP, recurrent acute pancreatitis; RDN, registered dietician nutritionist; s-MRCP, secretin magnetic resonance cholangiopancreatography; TPIAT, total pancreatectomy with islet autotransplantation.
[Refs 15,71,88,94.]

new to the adult healthcare system (15,71,88). Referrals to additional adult providers that need to be enlisted should be made at the initial visit. Short interval visits (every 3–6 months) with the gastroenterologist during the first year are recommended to help strengthen the new care relationship.

Patients with complex disease (e.g., frequent recurrent attacks of acute pancreatitis, anticipated need for pancreatic advanced endoscopy procedures, and need for multidiscipline care) may benefit from primary management or comanagement with an adult gastroenterology provider at a tertiary center. Gastroenterology societies also offer electronic solutions for the support of community gastroenterologists in the care of complex patients. GI OnDemand (giondemand.com), a joint venture between the ACG and Gastro Girl, Inc., offers peer-to-peer consultation, evidence based decision tools and patient directed educational programs assist physicians in the care of patients with complex disease.

During the comprehensive medication review and reconciliation, pain management, EPI, and nutrition supplements should be carefully reviewed because dosages, indications, and interactions (such as those related to reproductive health) may change. Pain control should also be carefully reassessed because certain interventions used in adult populations (e.g., antioxidant therapy and celiac plexus block) may not have been recommended or available under pediatric care. Referral to an adult pain management provider should be considered if the patient (i) is taking opioid pain medications, (ii) has daily or frequently relapsing abdominal pain, and/or (iii) has been previously managed by a pain specialist.

A narrative pertaining to abstinence from alcohol and smoking should continue in the adult healthcare setting. Best practices with reference to dietary choices and exercise should be reinforced. The extent to which the patient is able to independently manage their health care should be assessed because the youth may need to continue to work on transition skills in the adult setting. Because the young patient may have limited experience with independently contacting providers, the adult healthcare team should provide detailed (including after-hours) contact information. An action plan should be formulated for strategies to manage symptoms at home and/or circumstances to seek care in the urgent and inpatient setting. Table 3 provides recommendations for the adult provider after transfer of care. Although the progression of pancreatitis may be unavoidable in many patients, these interventions may prolong time to complications of pancreatitis (e.g., EPI) and help the patient realize independence and preserve an acceptable QOL (15,24).

Recommendations

- The adult team caring for a youth with CP should consist of a gastroenterologist, nutritionist, and case worker or psychologist at the minimum.
- Referrals to additional adult providers that need to be enlisted should be made at the initial visit.
- Patients should be referred to a gastroenterologist with expertise in pancreatic disease when possible.
- Attention to the comprehensive medication reconciliation at the initial visit in adult health care should include consideration of adult drug dosage recommendations, interactions, and side effects.
- Pain management should be reassessed based on recommendations and available treatments for adults.

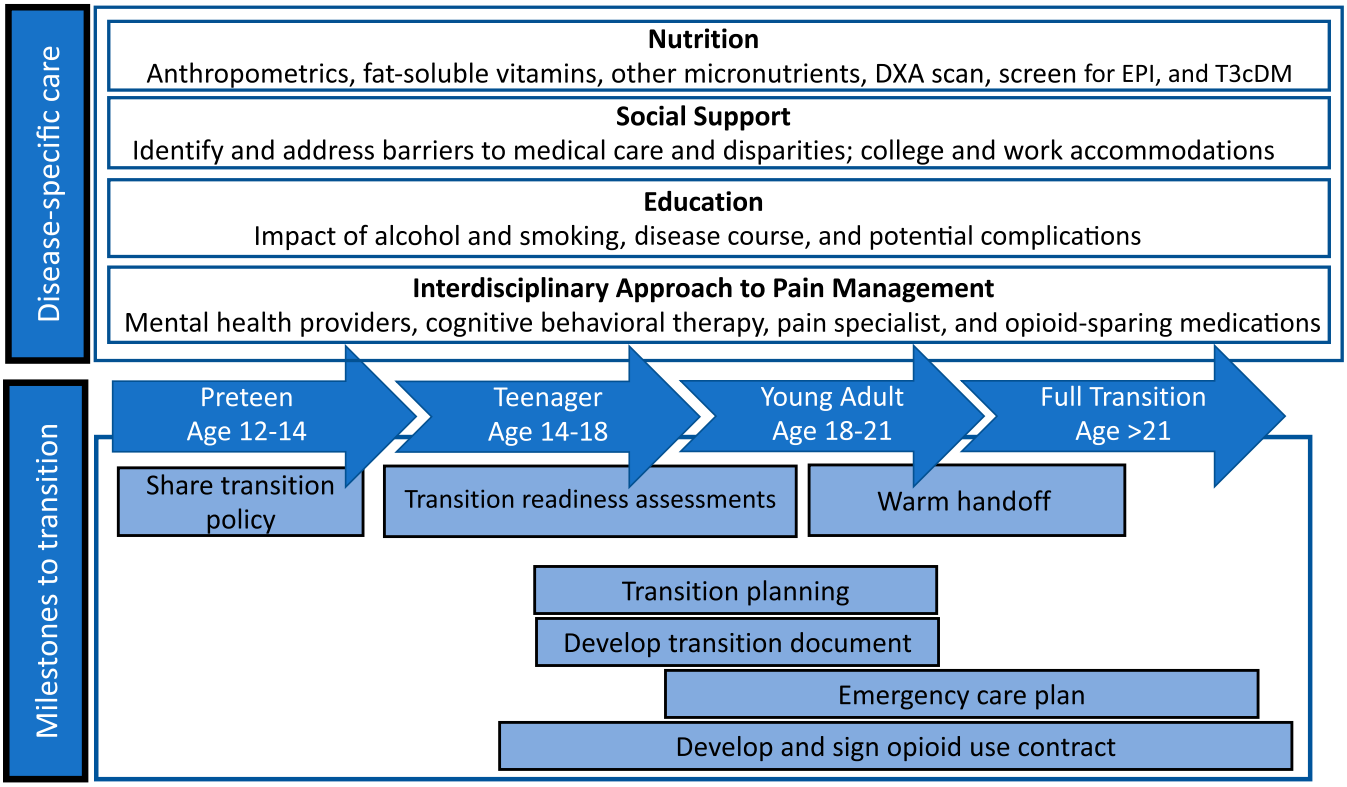

Figure 1. A schematic of the pediatric-to-adult transition/transfer in recurrent acute and chronic pancreatitis. Disease-specific concerns are illustrated through the transfer of care of a young adult from pediatric to adult health care DXA, dual-energy x-ray absorptiometry; EPI, exocrine pancreatic insufficiency; T3cDM, type 3c diabetes mellitus.

- Adult providers should assess healthcare independence of young adults and provide additional support where necessary.
- Visits every 3–6 months should occur initially to help the patient navigate the adult care world, establish referrals to other specialties, and develop long-term care goals.

DISCUSSION

The number of young adults transferring to adult care is large and for pancreas disease, is likely underestimated. As with other chronic diseases, young adults with RAP and CP need lifelong expert care. Transitional care and transfer programs face many obstacles including a lack of tools to assess transition readiness and no set age to initiate transitional care or transfer (89,90). We do not yet understand the links between transition readiness, adherence, and clinical outcomes; continuity and retention in care; and the impact and cost of interventions in the context of value-based care (91). The needs of young adults with childhood-onset conditions in the adult healthcare setting have yet to receive needed attention (5,92).

Aside from transition and transfer issues, there are many other unknowns in young adults with RAP and CP, such as metabolic and bone health outcomes, emotional experience and behavioral functioning, and the burden of psychological and psychiatric comorbidities. Data strongly suggest that teens would benefit from not taking up smoking or drinking, but this has yet to be proven in a longitudinal study, and it is not known whether complete abstinence is necessary or how to achieve this outcome.

Given these limitations, this guidance is based on expert opinion. We hope this document will serve as a blueprint to develop a multistep, comprehensive P2A transfer program for pancreatic disease, which is demonstrated in Figure 1. Formal feedback from stakeholders, including patients, parents/caregivers, and providers, need to be incorporated to develop a more meaningful and evidence-based process. We recommend that educational material and transition readiness tools be available on public platforms such as the ACG Practice Management Toolbox (https://gi.org/practice-management/toolbox/). Studies of the impact of a dedicated pancreatic P2A program on QOL, healthcare disparities, adherence with the medical treatment plan, repeat hospitalizations and healthcare utilization, and other outcomes measures, such as long-term productivity, achieving higher education, long-term employment, and others are needed.

Finally, it is anticipated that interventions early in the course of the disease will have the greatest impact on outcomes. Critical research, particularly in interventions to decrease or delay the onset of CP and its complications, will not be possible if young adults with pancreatic disease are not participating in a reliable, longitudinal follow-up (84).

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CONFLICTS OF INTEREST

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