

# A Systematic Review of Psychological Interventions for Adolescents and Young Adults Living With Chronic Illness

Ursula M. Sansom-Daly

University of New South Wales and Sydney Children's Hospital

Michelle Peate

University of New South Wales

Claire E. Wakefield

Sydney Children's Hospital and University of New South Wales

Richard A. Bryant

University of New South Wales

Richard J. Cohn

Sydney Children's Hospital and University of New South Wales

**Objective:** There is increasing recognition that adolescents and young adults (AYAs) with chronic illnesses experience common psychological challenges. This article reviewed published psychological interventions for AYAs with cancer, diabetes, juvenile idiopathic arthritis, sickle cell disease, and asthma. Common, efficacious intervention components were examined to generate clearer recommendations for future age-appropriate, evidence-based intervention development. **Methods:** Five databases including MEDLINE, MEDLINE In Process & Non-Indexed Citations, PsycINFO, EMBASE, and CINAHL, were searched for studies involving AYAs aged 10–30 years, using quantitative two-group methods, published from 1979–2010. Of 1,233 abstracts, 87 were extracted for further analysis and a final 25 studies were eligible for inclusion. Thirteen of these studies included AYAs with diabetes, 7 studies involved AYAs with cancer, and 5 included AYAs with other illnesses. **Results:** Educational interventions showed some significant positive results, particularly when targeted knowledge outcomes were measured. Several skills-based programs, some including parents, showed positive results, with moderate effect sizes. Interventions which taught communication skills, incorporated practical components (e.g., role-plays, homework), involved  $\geq 6$  sessions, and spanned at least 3 months in length, appeared more likely to achieve positive outcomes. **Conclusions:** Skills-based interventions delivered over multiple sessions may yield the most positive results in AYAs with chronic illness. Given the few peer-support groups eligible for review, their efficacy remains unclear. This review points to the need for intervention development that teaches adaptive coping skills, is grounded in theoretical frameworks, and adheres to strict randomization and independent assessments to evaluate efficacy in assisting AYAs adjust to chronic illness.

**Keywords:** chronic illness, adolescent, young adult, psychological adaptation, intervention studies

**Supplemental materials:** <http://dx.doi.org/10.1037/a0025977.supp>

Recent estimates indicate that ~20–30% of adolescents in Western countries are living with a chronic illness, and in 10–13% this condition significantly limits their daily functioning (Yeo & Sawyer, 2005). By definition, chronic illness has a biological,

cognitive or psychological basis, persists for over a year, imposes significant restrictions on aspects of functioning and requires compensatory or assistive care, support, medication, or other interventions (Stein, Bauman, Westbrook, Coupey, & Ireys, 1993). For adolescents and young adults (AYAs), the ongoing management of chronic illness can impose physical, emotional, and financial dependence at the time when increasing autonomy is the developmental goal. During this stage, individuals engage in identity formation, establish social competence, balance family and peer influences, develop and explore sexuality, and adapt to emerging intellectual abilities (Havighurst, 1972). Not achieving these significant milestones places individuals at heightened risk for poor adaptation within their future adult roles (Orr, Weller, Satterwhite, & Pless, 1984).

Across chronic illnesses, there appear to be some common challenges for adolescents and their families, but also some differences. While on treatment, diabetic and cancer patients, for example, both require constant monitoring and strict adherence to a medical regimen, with little room for the risky behaviors and experimentation that is often a part of peer relationships at this

This article was published Online First November 7, 2011.

Ursula M. Sansom-Daly, School of Psychology, University of New South Wales, Randwick, New South Wales, Australia, and Centre for Children's Cancer and Blood Disorders, Sydney Children's Hospital, Randwick, New South Wales, Australia; Michelle Peate, Prince of Wales Clinical School, University of New South Wales; Claire E. Wakefield and Richard J. Cohn, Centre for Children's Cancer and Blood Disorders, Sydney Children's Hospital, Randwick, New South Wales, Australia, and School of Women's and Children's Health, University of New South Wales; Richard A. Bryant, School of Psychology, University of New South Wales.

Correspondence concerning this article should be addressed to Ursula M. Sansom-Daly, School of Psychology, University of New South Wales, High Street, Randwick, New South Wales, Australia 2052. E-mail: [ursula@unsw.edu.au](mailto:ursula@unsw.edu.au)

stage (Morgan, Davies, Palmer, & Plaster, 2010; Sawyer, Drew, & Duncan, 2007). Once treatment for the cancer patients is complete, they only require intermittent follow-up, but live with the ongoing possibility of life-threatening events, and must also deal with the late effects of therapy. Consequently, cancer survivors experience ongoing illness-related demands and challenges into adolescence and young adulthood, even if treatment is completed at a young age. Patients with Sickle Cell Disease (SCD; Thompson et al., 2003), Juvenile Idiopathic Arthritis (JIA; Ireys, Sills, Kolodner, & Walsh, 1996), Cystic Fibrosis (Harrop, 2007), and asthma (Horner, 1995) have pain and uncertainty regarding future medical events as constant reminders of vulnerability for future episodes, which may complicate the developmental task of planning the future (Taylor, Gibson, & Franck, 2008). Pain and physical side effects, including disease-related changes in appearance, and extended time away from peers, may also contribute to disruptions to normal social, and identity development (Evan, Kaufman, Cook, & Zeltzer, 2006). The experience of developmentally advanced psychological issues, such as vulnerability to illness and mortality, may compound these disruptions (Taylor et al., 2008). Such stressors may place a great deal of strain on AYAs' emerging coping skills as they attempt to reconcile the constraints of their disease with normal life as a young person.

It appears that a young person's capacity to negotiate the effects of their illness, while navigating complex social relationships, is key to successfully managing these developmental disruptions (Olsson et al., 2003). Studies suggest that interventions that are tailored, age-specific, and developmentally appropriate are likely to be better received by AYAs (Zebrack, Chesler, & Kaplan, 2010). Thus, addressing the effects of chronic illness with appropriate therapeutic techniques may reduce the psychological impact of the experience. Unfortunately, there is a paucity of age-specific interventions that address psychological adaptation among chronic illness populations (Sawyer, Drew, Yeo, & Britto, 2007). This apparent gap in the literature means that many AYAs currently do not receive evidence-based psychological support as part of routine care. The tendency for AYAs to 'fall through the cracks' in health care systems split between pediatric and adult facilities may further constrain developmentally appropriate care and exacerbate the stress inherent in living with chronic illness during this stage (Kennedy & Sawyer, 2008).

Although there have been some recent reviews of interventions for adolescents with specific chronic illnesses, such as cancer (Seitz, Besier, & Goldbeck, 2009), small reported numbers have limited the quantity and quality of interventions that could be included in these. Chronic illnesses exert certain common developmental disruptions and psychosocial consequences on families and individuals (Eiser, 2003; Sawyer et al., 2007; Stein & Jessop, 1989). Accordingly, there are significant advantages to synthesizing research evidence across distinct literatures. In particular, delineating the common, efficacious intervention elements across disease groups may highlight what is useful to include in acceptable and developmentally appropriate programs of psychological support for AYAs living with chronic illness. Such evidence may also facilitate the borrowing of evidence-based models of psychological support for AYAs between illness populations.

The objective of this review was therefore to provide a systematic overview of all published, rigorously evaluated psychological

interventions for AYAs living with a chronic illness. Three questions were addressed:

1. What are the characteristics of the available psychological interventions targeted at AYAs with chronic illness, and what is their quality?
2. Which of these appear efficacious in addressing psychological adaptation?
3. What sample, methodological, or intervention characteristics are common among studies achieving positive effects on psychological outcomes?

## Method

Gold-standard systematic review procedures were followed, for the purposes of synthesizing the available evidence, and drawing recommendations for future research (Liberati et al., 2009). This involved determining, *a priori*, a complete set of inclusion and exclusion criteria, conducting a rigorous literature search across more than one database, using a standardized, independent abstract screening and study selection process, clearly documenting excluded studies, and using consistent data extraction methods.

## Search Strategy

Five electronic databases were searched, limited to human studies published in the English language. In each database searches for terms defining the age group (e.g., "Adolescent," "Young Adult"), the disease types (e.g., "Neoplasms," "Diabetes Mellitus"), the outcomes of interest (e.g., "Adaptation, Psychological"), and the studies of interest (e.g., "Intervention Studies") were run, and combined. Online Appendix 1 presents a complete list of database-specific search terms used.

## Study Inclusion Criteria

Studies published in a peer-reviewed journal from January 1979 to December 2010, which evaluated a psychosocial intervention for AYAs with a chronic illness were included in this review. Diseases included were cancer, diabetes, cystic fibrosis, SCD, asthma, or JIA. These diseases were selected because of the shared common elements in their experience, such as an uncertain and ongoing disease course. Certain conditions were excluded because they possess qualitatively distinct features from the other chronic illnesses. Chronic pain was excluded because of the dominance of daily aversive sensations and the frequent presence of chronic pain syndrome. Chronic fatigue syndrome was excluded because it is distinguished from the other conditions, which are associated with potential life-threat (e.g., see Eccleston, Morley, Williams, Yorke, & Mastroiannopoulou, 2002; Whiting et al., 2001). HIV/AIDS interventions were excluded because of their preventative health and behavioral change focus. Studies were included if:

1. All study participants were aged between 10 and 30 years during participation, regardless of their age at diagnosis. This broad definition was designed to capture all relevant interventions, including any drawing on the World Health Organization's definition of adolescence from 10

years of age (World Health Organization, 1977), international studies (Treadgold & Kuperberg, 2010), and those that predated the “AYA” coinage and age definitions (Hayes-Lattin, Mathews-Bradshaw, & Siegel, 2010).

2. Curative and/or ongoing disease management remained the overarching goal of the medical treatment being received by participants. Interventions developed for end-stage, palliative care patients were excluded.
3. Interventions were specifically designed to affect change in at least one psychosocial aspect of living with a chronic illness, ascertained through a study’s stated aims and outcome measures. Disease knowledge alone was not considered sufficient for inclusion; however, it is included where studies measured it alongside adjustment outcomes, to gauge the breadth of a program’s efficacy. Family interventions were included provided that they reported outcomes separately for AYAs; parent outcomes are not discussed here.
4. Studies used a quantitative, two-group controlled design, involving the administration of standardized measures at two or more time-points. Many inpatient settings precluded strictly randomized designs. These were not excluded; however, study randomization data was recorded.

Only the most recent published report of any given original intervention was included.

### Data Extraction

The resulting 1,233 abstracts were screened by two researchers (U.S.D., M.P.) using the inclusion criteria listed above. Interrater reliability was 96% (49 disagreements out of 1,233 abstracts). Full-text articles were extracted for all abstracts that either appeared eligible to at least one reviewer, or which did not yield sufficient information for review, to confirm eligibility ( $n = 87$ ). Consensus between the two authors was achieved by discussing and clarifying details against the full-text article. Studies not fitting the inclusion criteria were discarded (see Figure 1). To augment the electronic search, reference lists of included studies and table of contents of key journals were examined manually to identify additional relevant studies. This led to the inclusion of a further 10 articles.

The data shown in Table 1 were extracted from each eligible trial, and reviewed by two authors (U.S.D., M.P.). Detailed information on sample, methodology, intervention, and outcome measures, was examined. Although the principles outlined by Oxman (1995) guided study selection and analysis, the usefulness of a meta-analysis was constrained by the few consistent measures used both across psychological constructs and studies (Lipsey & Wilson, 2001). Similarly, indices of clinically significant change were not calculated. This was due the lack of available data on normative versus clinical adjustment across many disease-specific measures, as well as the difficulty in ascertaining “clinical” change in populations that may only be distressed at subclinical levels (Van Dongen-Melman, De Groot, Hahlen, & Verhulst, 1996). However, Cohen’s effect sizes were calculated where possible to index practical significance, where  $d = .2$ ,  $.5$ , and  $.8$  suggest a

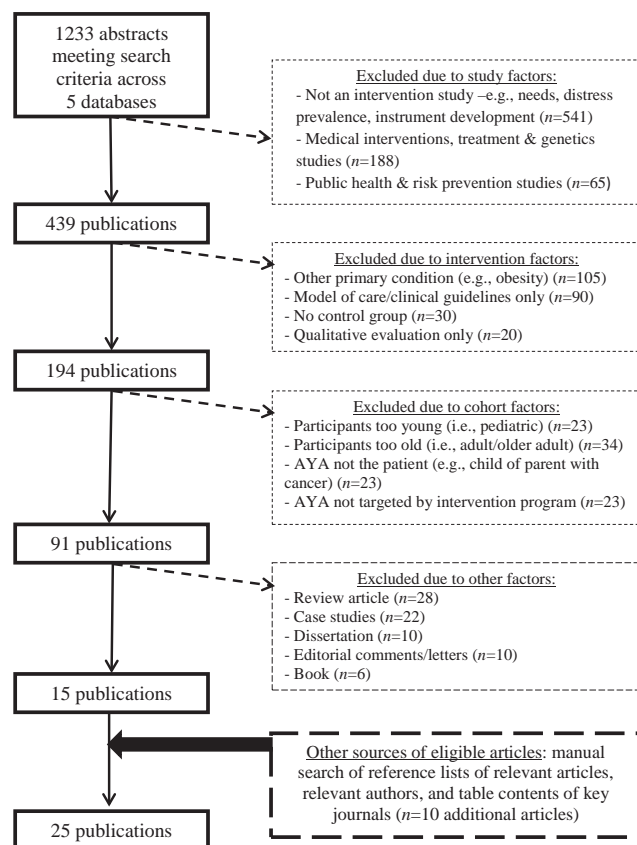


Figure 1. Reasons for exclusion of publications resulting from database search ( $n = 1,208$ ).

small, medium, and large effects, respectively (Thalheimer & Cook, 2002).

Fisher’s exact test was used post hoc to compare the relative frequency of particular intervention characteristics according to whether they had been successful in achieving at least one significant outcome, or not.

### Intervention Classification

In line with Plante et al. (2001), interventions were classified according to their primary goals and intended outcomes as (a) emotional/peer-support, (b) educational/psychoeducational programs, and (c) skills-based programs. Emotional/peer-support groups were defined as those aiming to improve psychological adaptation to illness through the provision of contact and discussion with peers, and emphasized support rather than the acquisition of knowledge, skills, or medical symptom-reduction. Camp programs were subsumed under the peer-support category, on the basis of their recreational group focus. Educational interventions aimed to enhance illness adjustment through the provision of information about the illness, its management, and related psychological issues. Skill-based programs were characterized as those including explicit and often practical training in adaptive coping strategies, to deal with current or future stressors. These were further classified according to whether they involved a parent to gauge the impact of family inclusion for AYAs.

Table 1  
Details Extracted From Each Eligible Trial

Category	Details
Study type	First author, year of publication, country
Sample characteristic	Sample size at time of randomization, chronic illness(es) included, age range (years), whether parents included
Intervention characteristic	Intervention duration, frequency and length of intervention sessions, mode of intervention delivery, type/training of interventionist
Study methods	Length of longest follow-up, comparison group type, randomization, outcome measures used
Intervention outcomes	Reported statistical significance of between-group differences ( <i>p</i> values), study group means

## Methodological Quality

The quality of each included study was assessed by two authors (U.S.D., M.P.). The quality assessment was based on Jackson, Cheater, and Reid's (2008) criteria, where aspects of the theoretical basis, methodology, statistical analysis, and reporting are assessed. Studies were assessed categorically as meeting each equally weighted criterion (yes, no, or unclear; Table 2). Interrater reliability was 95% (16 discrepancies across 325 criteria). Discrepancies between raters were resolved through discussion with clarification against the full-text articles where particular details were in question. The presence of intervention manualization and treatment fidelity checks were also examined. This involves the clear specification and standardization of intervention content and delivery, with independent ratings of the program's adherence to this (Mohr et al., 2009). Study quality was not a prerequisite for study inclusion, but is discussed below.

## Results

### Research Question 1: What Are the Characteristics of the Available Psychological Interventions Targeted at AYAs With Chronic Illness, and What Is Their Quality?

The 25 included studies are summarized in Table 3 (full study details are available as online supplementary material). Thirteen

included AYAs with diabetes, 7 with cancer, 2 with JIA, 1 with asthma, 1 with SCD, and 1 with both asthma and SCD. No eligible studies in cystic fibrosis emerged. Participant ages ranged from 10–29 years old. Parents were involved in six studies. Sample sizes ranged from  $N = 12$  to 375.

Between disease groups, there were some differences in the types of interventions utilized. Diabetes interventions had a greater proportion of skills-based interventions (8/13 or 62%) of which three (38%) involved the family. By contrast, in the AYA cancer literature only two interventions (of seven; 29%) specifically targeted the development of coping skills, one of which included the family. The remainder of cancer interventions were spread over peer-support (2/5, 40%) and educational models (3/5, 60%). The other illnesses (asthma, SCD, and JIA) only received educational and skills-based programs.

The quality of the studies was generally high (see Table 2). Quality assessment scores (2008) ranged from 42.3% (Study 1, as listed in Table 3) to 96.2% (Study 3). All studies provided a clear description of their aims/objectives, and most clearly described their study sample, data collection, and analysis. However, only six studies reported appointing a consumer representative (a lay-person living with the chronic illness) to inform study development (Studies 3, 9, 10, 18, 19, 23; Table 3). Only 32%, most in cancer, reported using a theoretical framework to guide their research (Studies 1, 2, 8, 10, 12, 13, 18, 21), although several others explicitly referenced cognitive, behavioral principles (see Online Appendixes). Nine studies (36%) did not adequately document recruitment data.

Study randomization and control group type can be seen in Table 3. The majority of studies were randomized ( $n = 19$ ). Twelve programs used either waitlist or usual care controls. Attention or support control groups, which involve contact with researchers or clinicians to control for the generic benefits of "nonspecific" therapeutic effects (Mohr et al., 2009), were used in 10 studies. Among the remaining studies, one used patient-referred friends as controls (Study 3), one study used a historical patient control (Study 4), and one study did not provide details (Study 1). Three diabetes interventions conducted three-arm trials including both a wait-list or usual control and an alternative form of psychological intervention (Studies 22, 24, 25). The only studies reporting intervention fidelity checks ( $n = 7$ ; Studies 14, 15, 20, 21, 23–25), explicit intervention manualization ( $n = 4$ ; Studies 20, 21, 24, 25), and control group manualization, such as specifying generic patient education or emotional support ( $n = 5$ ; Studies 13, 17, 20, 24, 25) were all skills-based interventions, suggesting adherence to stricter methods in this type of intervention.

Table 2  
Percentage of Studies Scoring a 'Yes' for Quality Assessment Criteria (Jackson et al., 2008)

	All studies $N = 25$	%
Explicit theoretical framework identified/literature review	9	36.0
Clear aims and objectives	25	100.0
Clear description of setting	21	84.0
Clear description of sample	23	92.0
Appropriate sampling procedure	23	92.0
Clear description of data collection	24	96.0
Clear description of data analysis	24	96.0
Provision of recruitment data	17	68.0
Provision of attrition data	20	80.0
Valid and reliable outcomes	19	76.0
Findings reported for each outcome	22	88.0
Evidence of consumer involvement	6	24.0
Strengths and limitations stated	22	88.0
Mean % of maximum possible score		83.1



Table 3  
Summary of Included Trials

No.	First author (year)	Country	N	Randomized	Control	Sample: Condition (ages)	Intervention duration <sup>†</sup>	Longest follow-up
Emotional/peer-support group interventions								
1	Daley et al. (1992)	USA	54	Yes	Unknown	Diabetes (12–16 years)	10 months	Postintervention only
2	Heiney et al. (1988)	USA	14	No	Usual care	Cancer (14–19 years)	6 weeks	Postintervention only
3	Schwartz et al. (1999)	USA	76	No	Healthy	Cancer (18–29 years)	3 days	2 months
4	Wang et al. (2008)	USA	182	No	Historical	Diabetes (12–18 years)	20 days	3–10 months
Educational/psychoeducational interventions								
5	Andre et al. (2001)	Sweden	17*	No	Usual care	JIA (13–19 years)	1 day (8 hr)	4 months
6	Canada et al. (2007)	USA	21	Yes	Waitlist	Cancer (15–25 years)	3 months	3 months
7	De Wit et al. (2008)	Netherlands	91	Yes	Usual care	Diabetes (13–17 years)	12 months	12 months
8	Hazzard et al. (2002)	USA	38*	Yes	Attention	Asthma and SCD (13–18 years)	3 days	Postintervention only
9	Jones et al. (2010)	USA	65	Yes	Attention	Cancer (12–18 years)	3 months	3 months
10	Kato et al. (2008)	USA	375	Yes	Attention	Cancer (13–29 years)	3 months	3 months
11	Løding et al. (2008)	Norway	19	Partially	Attention	Diabetes (13–17 years)	10 months	18–21 months
12	Rogers Fischl et al. (2010)	USA	88	Yes	Usual care	Diabetes (13–20 years)	9 months	Postintervention only
Skills-based interventions (AYAs alone)								
13	Boardway et al. (1993)	USA	19	Yes	Usual care	Diabetes (12–17 years)	3 months	9 months
14	Channon et al. (2007)	UK	66	Yes	Attention	Diabetes (14–17 years)	12 months	24 months
15	Grey et al. (2000)	USA	77	Yes	Attention	Diabetes (12–20 years)	12 months	12 months
16	Hains et al. (2000)	USA	14	Yes	Waitlist	Diabetes (12–15 years)	6 weeks	1 month
17	Hampel et al. (2003)	Germany	19*	No	Usual care	Asthma (14–16 years)	4 weeks	Postintervention only
18	Hinds et al. (2000)	USA	78	Yes	Attention	Cancer (12–21 years)	1 × 40 min session	6 months
19	Whittemore et al. (2010)	USA	12	Yes	Attention	Diabetes (13–16 years)	5 weeks	6 months
Skills-based interventions (parent/family inclusion)								
20	Barakat et al. (2010)	USA	53	Yes	Attention	SCD (12–18 years)	10 weeks	12 months
21	Kazak et al. (2004)	USA	150	Yes	Waitlist	Cancer (10–19 years)	1 day	3–5 months
22	Satin et al. (1989)	USA	32	Yes	Waitlist	Diabetes (12–19 years)	6 weeks	6 weeks
23	Stinson et al. (2010)	Canada	46	Yes	Attention	JIA (12–18 years)	12 weeks	Postintervention only
24	Wysocki et al. (2001)	USA	119	Yes	Usual care	Diabetes (12–17 years)	3 months	12 months
25	Wysocki et al. (2006)	USA	104	Yes	Usual care	Diabetes (11–16 years)	6 months	12 months

Note. JIA = juvenile idiopathic arthritis; SCD = Sickle Cell Disease.

\* Asterisk denotes AYAs being a sub-group of an overall sample (e.g., child and adolescent) for whom outcomes were analyzed separately. <sup>†</sup> Including booster sessions.

The measures used across studies varied widely, even within disease groups. For example, diabetes studies used 41 different measures in total, over half of which were diabetes-specific. Similarly, 28 different measures were used across the 6 intervention studies in AYAs with cancer, including several purposely designed, yet nonvalidated measures. Even disregarding particular measures used, at least 18 different psychological constructs were used across studies to index 'adjustment,' including: anxiety, depression, posttraumatic stress symptoms, coping, self-efficacy, locus of control, perceived stress, quality of life (QoL), goal hindrance, attitudes, happiness, hopefulness, hopelessness, self-esteem, symptom distress, perceived social support, body image, and sexual concerns. There were also some inconsistencies in the match between constructs measured and intervention type. Only six of eight (75%) interventions classified as educational included a measure of knowledge or perceived knowledge (several of which were nonvalidated), while only four of six (67%) family focused interventions included a measure of family adjustment. Most studies (18 of 25) included follow-up measurements beyond the immediately posttreatment period; however, these varied from 1 to 24

months postintervention. Few studies ( $n = 5$ ) incorporated outcome measures administered by blind or independent assessors (Studies 9, 10, 15, 16, 25).

## Research Question 2: Which Interventions Appear Efficacious in Addressing Psychological Adaptation?

Nineteen (out of 25; 76%) interventions yielded a significant effect on at least one psychological outcome measure. This dropped to 14 studies (56%) if studies achieving significant effects only on purposely designed, nonvalidated measures were excluded.

**Nondirective emotional and peer-support.** Four interventions were identified with the common objective of facilitating psychological adjustment through peer support, of which three (75%) showed significant effects on at least one psychological measure. These studies included a mentoring program for AYAs with diabetes (Study 1), and two other residential camps delivering peer-support and education (Studies 3, 4). The remaining cancer peer-support group did not yield any significant results (Study 2).

**Education and/or psychoeducation models.** Eight educational interventions were captured. One multisession, counseling intervention delivered by health care professionals yielded no significant results on QoL (Study 11). However, the other educational interventions ( $n = 7$  or 88%) showed small to very large improvements on at least one of their outcome measures. The domains of improvement differed greatly between interventions, and included psychological domains such as coping, QoL, and symptoms of distress. Two psychosexual/reproductive-health focused interventions (Studies 6, 12) yielded significant effects (of at least medium size) in areas related to reproductive and sexual knowledge, as well as attitudes, intentions, and confidence. Two of the three computer-mediated interventions, both in AYAs with cancer (Studies 9, 10), achieved positive effects on health locus of control and disease-related knowledge; a third computer-based intervention in SCD and asthma patients showed significant effects on a pediatric coping measure (Study 8).

#### **Adaptation and coping skills training interventions**

**Coping skills for AYAs alone.** Four (57%), of the seven skills-based interventions, showed medium to very large significant effects. Most included regular practice of cognitive-behavioral techniques such as cognitive restructuring, problem-solving, goal-setting, and role-playing coping strategies, across a minimum of four sessions (Studies 13–17, 19). Mostly, the group-based, multisession programs showed at least one positive outcome (Studies 13, 15, 17). Two interventions were delivered individually; one single-session intervention teaching self-care coping strategies to cancer patients showed no positive effects (Study 18). The other, a multisession motivational interviewing program for AYAs with diabetes, showed several positive results at follow-up (Study 14).

**Multifamily/parent involvement in coping skills.** Several skills-based programs also included parents and other family members. Many of these interventions incorporated elements of behavioral family systems therapy, and utilized the multifamily discussion group format of delivery (Studies 21, 22, 24, 25). Five of the six family focused coping skills programs (83%) achieved medium to very large positive effects. However, of the four studies that measured family variables (e.g., family conflict, communication) only two showed significant effects on these measures.

The majority of the multisession family interventions in diabetes (Studies 22, 24, 25) and JIA (Study 23) attained positive outcomes on some measures, in particular those concerning family or parent-adolescent dimensions, as well as QoL. Parents had varied levels of active involvement; however, two trial diabetes programs that incorporated a particularly active role for parents (through parent “simulation” of diabetes management) both reported some positive results (Studies 22, 25).

### **Research Question 3: What Sample, Methodological, or Intervention Characteristics Are Common Among Studies Achieving Positive Effects on Psychological Outcomes?**

Table 4 depicts the proportion of interventions that appeared successful, according to particular study characteristics they possessed. For the purposes of this analysis, the achievement of at least one significant positive outcome on a psychological measure was used as the general index of study “success.” When examined

across all chronic illnesses, few significant differences in the characteristics of successful versus unsuccessful interventions emerged (see Table 4 for  $p$  values). However, several trends emerged, which may nevertheless explain some of the variance in intervention efficacy.

**Sample characteristics.** Although only a minority of trials in this review ( $n = 4$ ) targeted AYAs selected for greater need of intervention (i.e., secondary prevention) there appeared to be little difference between the efficacy of primary and secondary prevention trials. In fact, when limited to validated outcome measures, there was a trend for slightly more primary prevention-level trials to achieve significant effects ( $p = .600$ ). Studies that included the family appeared to show significant results more often than those without this inclusion, although this was nonsignificant.

**Methodology characteristics.** Many of the included studies had small sample sizes and consequently may have been underpowered to detect significant effects. As a crude comparison, there was a higher rate of intervention success among interventions with at least 25 participants per group. Further, among successful interventions the average sample size was  $N = 86$  ( $SD = 83.4$ ) compared with  $N = 32$  ( $SD = 27.5$ ;  $p = .133$ ) among interventions yielding no significant effects. Random assignment to groups and treatment fidelity checks also appeared to be more common to interventions showing significant effects. In addition, there was a trend toward fewer studies including a follow-up  $\geq 6$  months detecting significant effects than those with shorter follow-ups. Consistent with this, the average longest follow-up of studies with at least one significant outcome was (nonsignificantly) shorter than in studies that had not achieved this (5.7 months,  $SD = 6.4$ , vs. 7.4 months,  $SD = 7.3$ ;  $p = .579$ ). Regarding the measurement of intervention success, a somewhat higher proportion of studies that included generic psychological (as opposed to disease-specific) measures, and those that included a measure of positive adjustment or resilience, showed significant effects.

**Intervention characteristics.** Interventions with six or more sessions over time appeared to have somewhat higher success rates. Successful studies had significantly more intervention sessions on average than did studies with no significant effects ( $M = 8.4$ ,  $SD = 6.3$  compared with  $M = 5.3$ ,  $SD = 2.9$ ;  $p = .022$ ). Time-span of contact also appeared to be a powerful factor: interventions involving contact for more than 3 months demonstrated a greater success rate, and this approached significance. The average length of treatment among successful interventions was 4.7 months (or 18.8 weeks,  $SD = 19.9$ ) compared with 3.0 months (or 11.9 weeks,  $SD = 16.1$ ) in studies that showed no effects ( $p = .380$ ). Neither face-to-face contact nor peer-to-peer delivery (in groups of AYAs) appeared to significantly impact intervention success.

Several specific intervention elements emerged as potentially important for intervention success. When specific types of “coping skills” were examined, it appears that teaching skills, and particularly communication skills, are key to intervention success. In such skills-based interventions, the delivery of this content by a psychology- or counseling-trained professional also seemed to confer a greater likelihood of success. Incorporating role-play or other practical components ‘in-session,’ as well as implementing homework practice exercises out of session also appeared to be a common element to successful interventions, though again, neither difference was significant.

Table 4

*Sample, Methodology, and Intervention Characteristics of Trials Reporting  $\geq 1$  Significant Effect on a Psychological Outcome Measure*

		Achieved significant result on $\geq 1$ outcome	Significance of difference in proportion
	<i>n</i>	<i>n</i> (%)	<i>p</i> -value
Sample characteristics			
Selected for distress levels/higher need			
Yes	4	3 (75)	1.000
No	21	16 (76)	
Included parent/family			
Yes	6	5 (83)	1.000
No	19	14 (74)	
Methodology characteristics			
<i>n</i> $\geq 25$ per group			
Yes	12	10 (83)	0.390
No	13	8 (62)	
Randomized assignment to groups			
Yes	20	16 (80)	0.562
No	5	3 (60)	
Intervention incorporated fidelity checks			
Yes	7	6 (86)	0.637
No	18	13 (72)	
Attention control group			
Yes	9	6 (67)	0.630
No	16	13 (81)	
Length of postintervention follow-up $\geq 6$ months			
Yes	10	6 (60)	0.175
No	15	13 (87)	
Included disease-specific psychological measures (not simply measures of disease knowledge)			
Yes	18	13 (72)	0.637
No	7	6 (86)	
Included measures of positive adjustment or resilience*			
Yes	17	13 (77)	0.630
No	8	5 (63)	
Intervention characteristics			
Intervention duration $\geq 6$ sessions spaced over more than 1 day			
Yes	14	11 (79)	1.000
No	11	8 (73)	
Contact over $\geq 3$ months (including booster sessions)			
Yes	13	12 (92)	0.073
No	12	7 (58)	
Intervention delivery includes face-to-face contact			
Yes	21	16 (76)	1.000
No	4	3 (75)	
Intervention involved AYAs in groups (AYA to AYA peer interaction)			
Yes	11	8 (73)	1.000
No	14	11 (79)	
Intervention involves the formal teaching of problem-solving skills			
Yes	12	9 (75)	1.000
No	13	10 (77)	
Intervention involves the formal teaching of communication skills			
Yes	10	9 (90)	0.345
No	15	10 (67)	
Intervention included role-play or practice components ‘in session’			
Yes	14	11 (79)	1.000
No	11	8 (73)	
Intervention included homework or practice exercises between sessions			
Yes	6	5 (83)	1.000
No	19	14 (74)	
Delivered by a professional with psychology/counseling training (skills-based interventions only)			
Yes	10	8 (80)	0.203
No	3	1 (33)	

\* Included measures of coping, self-efficacy, adjustment, role skills, self-esteem, hope, happiness, locus of control.

In addition to yielding the most psychological interventions, and the only interventions evaluated in a three-group controlled design, diabetes programs demonstrated a higher rate of success (78% with  $\geq 1$  significant result) relative to cancer interventions (71%). Relative to interventions in cancer and other diseases, diabetes interventions showed a significantly greater proportion of studies with: follow up of at least 6 months (8/13;  $p = .041$ ), teaching of problem-solving skills (13/13;  $p = .039$ ), and a higher proportion of use of illness- (diabetes) specific psychological measures (12/13;  $p = .030$ ). Diabetes programs also showed trends toward more studies where participants were selected according to level of distress/need (4/13 compared with 0/12 in other diseases;  $p = .096$ ), more studies utilizing randomized assignment to groups (12/13,  $p = .160$ ), and greater implementation of homework practice between sessions (5/13 compared with 1/12 in other diseases;  $p = .160$ ).

## Discussion

The experience of chronic illness during adolescence and young adulthood may have lasting implications for individuals' development and progression into well-functioning adulthood. Synthesizing evidence across studies in AYAs with chronic illnesses may inform the selection of viable, evidence-based models of psychological intervention to ensure positive adjustment in this population. To this end, this review examined 25 psychosocial interventions for AYAs living with cancer, diabetes, JIA, asthma, and SCD. Relative to the overall scope of the search, the number of appropriate interventions included was small, indicating that there remains a paucity of rigorously evaluated psychological interventions for this group. It is encouraging to note, however, that almost half of the included interventions ( $n = 11$  or 44%) were published in the past 5 years; this may indicate growing attention to this population.

## Implications for Future Intervention Studies

The majority of intervention studies included in this review achieved positive effects on at least one psychological measure. Studies that measured positive growth (e.g., coping, self-efficacy, well being) rather than only indexing distress levels seemed to have a higher proportion of significant outcomes, suggesting that both aspects to adjustment are important to assess in this generally resilient group. Further, across intervention types it seems that the level of "match" between active therapeutic elements and target outcomes is important in gauging intervention efficacy. There was a great degree of variability and some inconsistency apparent in how psychological distress and adjustment was measured in this sample of studies. Not all educational interventions measured knowledge outcomes, and not all family interventions indexed adjustment at the family level. Studies that achieved positive outcomes often appeared to have a clearer link between their measures and intervention components, such as examining stress levels in stress management training programs (e.g., Boardway, Delamater, Tomakowsky, & Gutai, 1993), and diabetes-related conflict in programs that specifically targeted this (e.g., Wysocki, Greco, Harris, Bubbs, & White, 2001; Wysocki et al., 2006). By contrast, educational interventions often did not significantly

change psychological or interpersonal outcomes. Most studies already index multiple outcome measures; however, future intervention studies should more clearly delineate, measure, and report both the proposed mechanisms expected to underlie intervention success, as well as the outcomes reflective of this change. This may be assisted through designing studies scaffolded by a specific theoretical framework. Although the designation of a theoretical framework does not guarantee the delivery of positive outcomes, the presence of an overarching theory in guiding intervention design should entail a thorough consideration of what key elements are expected to affect change, how these may best be modified, and how process factors may be measured in assessment.

Several critical program features also emerged. A key finding of this review is the importance of teaching skills—particularly communication skills—and including practical (e.g., role-play, homework exercises) elements both in- and between sessions. Unlike peer-support programs, in skills-based interventions, participants not only gain benefits through sharing disease-related thoughts and emotions, but also by learning ways to identify and change maladaptive thought and behavior patterns. Although the majority of these programs were delivered in a group format, Channon et al.'s (2007) individual-based, motivational interviewing intervention demonstrated positive results, suggesting that the active benefits of this model may be successfully adapted to different groups. The finding that skills-based interventions had a greater "success rate" when delivered by a psychology or counseling trained professional may also relate back to these practical elements. Discipline-specific training in these professions may further increase the likelihood that modeling, role-playing, and other interactive practice elements may be used in an intervention, or enhance the interventionist's confidence in doing so.

Further, interventions which are multisession in format and involve contact over a longer time period appear more likely to be successful. Therapeutic contact over a longer period of time may be essential to the development, practice, and application of skills, in a manner which is more gradual, tailored to participants' needs, and scaffolded by a greater level of interventionist and group support. This may explain the emergence of not only disease-specific gains but also evidence of general adaptation in two such interventions (Grey, Boland, Davidson, Li, & Tamborlane, 2000; Hampel, Rudolph, Stachow, & Petermann, 2003). By contrast, shorter interventions may necessitate a more didactic, information-delivery format. This may not be optimal if the goal is to facilitate the practical acquisition of behavioral skills.

In this review it did not appear that the success of interventions—skills-based or otherwise—was linked to participant selection methods. The similar success rates between primary and the few secondary trials in this review may reflect the vulnerability of this population as a whole (Varni, Limbers, & Burwinkle, 2007). This may also attest to the potential benefits of building coping skills in a preventative capacity in this group, to buffer young people from future stress. However, given that none of the included studies screened for baseline psychological variables such as distress or coping, strong conclusions cannot be drawn regarding the usefulness of preintervention screening.

Despite evidence highlighting the importance of peers for AYAs with chronic illness, the peer support-focused interventions in this



review did not demonstrate consistently positive results. In fact, across all intervention types, programs delivered in groups of AYAs were not more likely to show improved psychological outcomes. Compared with the skills-based interventions, intervention manualization and fidelity checks were reported less often by peer-support group trials. This makes it difficult to discern the key elements involved in such interventions and the relative contributions of nonspecific (e.g., peer-support) versus specific (e.g., positive reframing) intervention elements to a program's success or lack thereof. Peer-support groups also tended not to be randomized, not to include long follow-ups, and had varying types of control groups. These factors mean that at present it is difficult to estimate the potential of peer-support groups to positively enhance adjustment outcomes of AYAs with chronic illness.

While a peer-focus did not appear to enhance positive adjustment outcomes, parent or family inclusion did appear to lead to better outcomes among the few studies that incorporated it. These results are consistent with the reciprocal importance of family functioning to a young person's coping, as well as the effects of a young person's chronic illness on the family (Rait et al., 1992). Targeting illness-related distress and adjustment also seems appropriate given some evidence supporting the concordant nature of clinical, intrafamilial posttraumatic stress symptomatology, and the associations that this may have with general family functioning (Alderfer, Navsaria, & Kazak, 2009; Kazak, Alderfer, Rourke, et al., 2004). Given the inherent developmental challenges of this period, it is likely that ongoing family pressures also contribute to the adjustment of AYAs living with the ongoing impact of chronic illness. This may include issues such as communication regarding parent-adolescent role boundaries, discipline, and appropriate expectations (Wakefield, McLoone, Goodenough, et al., 2010; Wakefield, McLoone, Sansom-Daly, et al., 2010). Several promising, multisession programs have been presented here, targeting family adjustment, communication, and conflict (Wysocki et al., 2001, 2006) and family level posttraumatic stress symptoms (Kazak, Alderfer, Streisand, et al., 2004). Such programs might be usefully adapted to AYAs living with other chronic illnesses, to equip families with further skills.

## Limitations

Reflective of the literature as a whole, this review was somewhat constrained by the variety of terms and definitions that surround the adolescent and/or young adult age group compared with the relatively recent coinage of the "AYA" term (Hayes-Lattin et al., 2010). Nevertheless, by adopting a comprehensive search strategy, and reviewing several chronic illness literatures, this study provides the broadest selection of psychological interventions appropriate to this age group. This enabled us to focus on quantitative studies for which a control group and measurement across multiple time-points was present, and is the most rigorous synthesis of the literature currently available.

This review is limited by its inclusion of only peer-reviewed articles published in English, thereby excluding published studies in other languages, or unpublished work (e.g., dissertations). There is evidence to support the existence of publication bias in clinical research, where studies with null results are less likely to be published (Hopewell, Loudon, Clarke, Oxman, & Dickersin,

2009). Consequently, there may be evaluations of interventions for AYAs outside the published literature, and that might have altered or tempered the present findings. Consequently, the current finding that the (largely successful) diabetes interventions had significantly longer average follow-ups, should be treated with caution. While it may be the case that the elements critical to intervention efficacy have been successfully distilled in the diabetes literature, the "file drawer effect" cannot be excluded. That is, studies that achieve null results at a shorter time-point may have great difficulty in publishing these results even after a long-term follow-up. Publication bias may also partly explain the minority of published studies across illnesses that included a long-term follow-up.

The variability of existing interventions for AYAs in their methodological approaches, presence and type of theoretical basis, psychological targets, therapeutic strategies, and the critical time-point of intervention (e.g., cancer treatment vs. survivorship) also limits the conclusions that may be drawn. Similarly, few included studies used an attention control, to control for the generic benefits of supportive contact. The wide variability in intervention characteristics observed also meant that in the present analysis, little statistical evidence to support the recommendation of particular intervention elements as critical to their success was possible. Consequently, the observations gleaned from the current review remain tentative and at the level of trends. Despite the limitations to such post hoc analyses, the emergence of several statistically significant differences in the intervention characteristics among the diabetes literature, compared with cancer and other chronic illnesses, suggests that there are nevertheless several intervention characteristics that may be more important to intervention success. These conclusions should be taken with caution, however, given the post hoc nature of the analyses conducted, as well as the rather liberal criterion used to define intervention success, where only one statistically significant effect was required, even among trials using multiple outcome measures.

The tendency for emotional or peer-support groups to be evaluated either qualitatively (using interviews or focus groups), or using only a pre-post design without a control group (Campbell, Phaneuf, & Deane, 2004) meant that only four examples were able to be included in this review. Evidence points to the importance of peer interaction in AYAs, and the increasing incorporation of peer-support/interaction elements in the care of AYAs with some chronic illnesses (e.g., cancer; Morgan et al., 2010). The apparent disconnect between the increasing availability of such peer-based interventions, and their lack of empirical evaluation, calls for further study.

The conclusions of this review are also limited by several key methodological limitations common to the AYA chronic illness literature. First, reflective of the relative rarity of chronic illness in AYAs, small sample sizes leading to underpowered studies appear to be the norm rather than the exception, reducing the likelihood of even the most rigorous trials achieving a significant result. Internet-based interventions may prove one method of recruiting more participants from a wider area, including rural/remote locations. Unfortunately, few Web-based interventions were included in this review, and these were disparate in focus and targets. However, positive results were obtained for three online educational models. Only one study (Whittemore, Gray, Lindemann,

Ambrosino, & Jaser, 2010) evaluated an Internet-based support group program, and was unable to detect significant effects, possibly because of its small sample size. Future evidence will be critical to better evaluate the potential of Web-based models, including their capacity to deliver psychological benefits besides education (e.g., coping skills training).

Second, a vast array of psychosocial outcome measures appears to be in use, both within and across the chronic illnesses. Further, several studies yielded significant effects only on disease-focused psychosocial questionnaires, or on purposely designed, nonvalidated study measures, rather than on mainstream psychological measures. The appeal of disease-specific measures reflects the dearth of measures sensitive enough to detect subclinical-level differences in distress between different populations (Perrin, Stein, & Drotar, 1991; Van Dongen-Melman, et al., 1996). This is disadvantageous both empirically and clinically, as the use of such measures precludes estimation of the relative success of an intervention, preventing its application in other groups. Future research is needed to examine the extent to which different distress and adjustment measures are sensitive to change within different chronic illness populations.

Finally, it is difficult to ascertain the extent to which interventions are age or developmentally appropriate when large age spans are common (e.g., 12–19 years). In only a few papers were subanalyses conducted according to smaller age ranges. This is likely impacted by small sample sizes, but is an important consideration when the intellectual, emotional, and psychological maturity of participants changes so significantly over even a few years (Petersen & Leffert, 1995). In addition, the few studies that included a consumer representative to inform the intervention content and delivery suggests that, although this issue is gaining the attention of funding bodies, in research it is still not common practice. This may mean that crucial details pertaining to the developmental appropriateness of the interventions are overlooked.

### **AYA Chronic Illness: Challenges for the Literature and Future Directions**

Across the chronic illnesses reviewed, research coming from the diabetes literature appears to be the most advanced in methodological rigor, and is the only literature in which three-armed trials, comparing different “active” interventions, have been conducted. Future interventions in other chronic illnesses may benefit from modeling their interventions on those developed in AYA diabetes populations, and this review may be used as a guide to some particularly useful examples. However, the extent to which the trajectory, management, and psychological impact may be aligned across different chronic illnesses remains poorly understood. There may be critical distinctions between the practical and psychological impacts of managing different conditions. Consistent with this, there is some evidence for differential effects of chronic illnesses on the health-related QoL of children and adolescents (Varni et al., 2007). For example, the experience of long-term monitoring for cancer recurrence may be quite different to the more proactive daily monitoring of insulin required in diabetes. Each illness may also have its own distinctive stressors; whether regarding diet in diabetes (Huus & Enskär, 2007), pain and activity levels in asthma, JIA, and CF (Harrop, 2007; Rhee & Steeves, 2007) or physical

scarring, side effects, or sexual/reproductive late effects in cancer survivorship (Carpentier & Fortenberry, 2010; Evan et al., 2006). Even within broad categories of illnesses (e.g., cancer) specific diagnoses may carry distinct implications for treatment length and severity, side effects, prognosis, and risk of medical late effects within illnesses. It is crucial that future research better characterize distress and “normal adjustment” in the context of each condition.

In a similar way, it is important that future research better conceptualize the patterns of illness-related distress and adjustment within families, and the extent to which family adjustment outcomes are intertwined across chronic illness literatures. At present this is limited by the few family level studies that have been developed, and the widely varying models of distress, adjustment, and coping that are currently in use across chronic illness literatures. Despite the common demands of adolescence, practical illness demands may interact with family- and parent-child dynamics in distinct ways across conditions. This may also help to address the multitude of psychological models and measures currently in use to gauge intervention success and individual adjustment.

The results presented here strongly suggest that there is a role for skills-development in interventions for AYAs living with chronic illness. However, researchers need to consider what particular skills are required of AYAs to effectively manage their specific disease. AYAs with diabetes require strict and ongoing medical adherence to prevent severe complications in the short-term or ill health later in life (Daley, 1992). AYAs living with cancer similarly require long-term follow-up and surveillance because of their heightened risk for medical late effects. However, after their defined treatment period this involves fewer active treatment elements, and greater emphasis is therefore placed on their capacity for the psychological maturity, responsibility, and self-sufficiency to independently heed follow-up requirements in the long term (Butow et al., 2010). Such considerations may guide what is necessary to include and measure in an intervention.

Given the varied success of the presented interventions, determining methods of delivering such content in a way which is acceptable and effective in the AYA age group also appears an urgent priority. While face-to-face delivery did not appear essential to intervention success, two of the three computer-mediated interventions achieved positive results. Recent evidence indicates that almost half of AYAs with chronic illness connect to the Internet at least multiple times weekly, and in women with chronic illness this is significantly greater than in their healthy peers (Suris, Akre, Berchtold, Belanger, & Michaud, 2010). Further, AYAs appear highly amenable to receiving psychological support delivered through the Internet. One recent study, in AYAs with cancer, found that chat or support group features involving peers was the second-most desired Web site feature, desired by 75% of the AYAs surveyed (Schiffman, Csongradi, & Suzuki, 2008). In addition to increasing the developmental appropriateness of AYA interventions, the “portability” of such approaches may lessen the high rates of attrition that have been recently reported in pediatric psychological interventions, by increasing the flexibility of intervention delivery and thus minimizing participant burden (Karlson & Rapoff, 2009).

## Recommendations

One of the compelling observations from the current review is the lack of adherence to CONSORT guidelines (Schulz, Altman, & Moher, 2010) in most published studies to date examining treatments for AYAs with chronic illness. The failure to ensure randomization, blind assessments, well-specified and manualized treatment protocols, and treatment fidelity checks raises questions about the conclusions that can be drawn from a number of these studies. Future intervention studies need to adhere to guidelines for reporting clinical trials (Schulz et al., 2010). The wide variety in number and type of outcome measures evident in the AYA chronic illness literature further suggests that it will be important for future studies using multiple outcome measures to "register" their intended primary outcome measures, consistent with the CONSORT methodology. Study registration would also ensure greater equality in publication, and avoid the aforementioned "file drawer effect." In addition, the following recommendations for future intervention studies in AYA chronic illness are offered:

1. AYAs' ability to successfully manage their chronic illness may be boosted through the use of skills-based programs. Communication strategies appeared particularly effective, and the incorporation of in-session practice and homework elements added to this. Delivery of these practical, skills-based elements by a psychologist, counselor, or similarly trained interventionist also appears important.
2. In an effort to better engage AYAs in programs targeting psychological adaptation, future studies may consider using a computer-mediated delivery format. Many successful programs already-developed may be amenable to translation into this medium using the assistance of video-conferencing, chat, and other interactive technologies.
3. Across intervention types, it appears that length of intervention contact is a key determinant of success. It is recommended that future interventions incorporate at least one booster session to extend the intervention time-span to a minimum of three months, and involve multiple (preferably  $\geq 6$ ) sessions over time.
4. Intervention trials should include a longer follow-up after treatment completion (ideally be at least 12 months) to assess the longevity of the developed intervention. This is especially important in cases of illness recurrence or symptom worsening.
5. Where possible, attention control groups should be used to better distinguish the specific effects of an intervention from the generic benefit of receiving therapeutic attention. This is particularly important considering the difference in treatment experience AYAs of different ages may receive at pediatric and adult centers.
6. Interventions and control groups should be manualized as specifically as possible to enable a clearer identification

of effective components, as well as easier comparison across studies.

7. Consulting lay consumer representatives throughout intervention development and implementation is particularly important when working with this age group and may increase the developmental appropriateness of interventions.
8. Based on evidence, a clearer linkage to an appropriate theoretical model, and careful consideration of an intervention's scope and targets, researchers should identify outcome measures that capture changes in areas or skills that are explicitly addressed by the intervention. As disease-specific measures do not seem to offer any systematic advantage, researchers may wish to include both generic and disease-specific measures of adjustment. Measures that enable the identification of positive changes or "resiliency" factors may also be particularly powerful in demonstrating adjustment in this population.
9. Future studies should endeavor to increase sample sizes to enable a more thorough characterization of participants according to baseline coping or distress, prognosis, treatment severity, treatment adherence, personal and family psychological history, and age. This may be facilitated by increasing multisite collaboration, and including individuals with different diseases, diagnoses, or prognoses, and controlling for these factors in later analyses. Future intervention studies should also endeavor to analyze outcomes according to more tightly confined age-brackets within the full sample.
10. Where sample sizes permit, it may be beneficial for future studies to index the relative benefits gained by participants according to baseline psychological factors related to an intervention's focus. In addition to being a more cost-effective model of intervention, gaining evidence for a graded approach may address the issues inherent in intervening in generally resilient populations (Kazak, 2005).

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Received January 19, 2011

Revision received August 15, 2011

Accepted August 15, 2011 ■