Supplementary Materials 2. Additional content relating to Chapter 3: Review 2

Table 1: Review 2 inclusion and exclusion criteria

Criteria	Specification

Population	Include if:
	o Children and young people aged 25 years old or younger with any long term physical health condition.
	  o Long term physical health conditions are defined as diagnosed physical health conditions, with an expected duration of at least three months, where cure is considered unlikely, causing limitations in ordinary activities and necessitating medical care or related services beyond what is usual for the age in question.
	  o Include samples of young adults where we might be able to focus on data for the 18-25 year old subsample.
	  o Long term conditions may also be referred to as chronic illness/disease/conditions or complex health needs.
	  o Symptoms of mental ill health will not usually be measured in qualitative studies, therefore mental ill health was not an inclusion criteria.
	o The parents and families of children and young people aged 25 years old or younger with any long term physical health condition.
	o Those involved in the delivery of interventions to improve mental health and wellbeing in children and young people with long term physical conditions.
	o
	Exclude if:
	o Long term condition is obesity – in line with Review 1.
	o All participants have moderate or severe learning/intellectual disabilities (i.e. IQ < 70).

Intervention	Include if: o Any intervention including non-pharmacological and pharmacological. o Intervention aims to improve child/young person mental health and wellbeing. o Intervention can target children and young people’s mental health directly (i.e. children and young people are recipients) or indirectly (e.g. parenting interventions). o Participants or their relatives do not have to have received or delivered an intervention, but may reveal attitudes towards an intervention in development or interventions they have chosen not to receive. Exclude if: o Focus on mental health *service provision*, rather than specific interventions for children and young people with long term physical conditions.
Outcomes	Include: o Attitudes, experiences, perceptions and understanding of children and young people with long term conditions, regarding interventions for their mental health. o Attitudes, experiences, perceptions and understanding of parents whose children have long term conditions regarding interventions for the child’s mental health. o Attitudes, experiences, perceptions and understandings of practitioners who have delivered mental health and wellbeing interventions for children and young people with long-term conditions.
Study design	Include if: o Qualitative data collection and qualitative data analysis. o Examples of methods to be included: interviews, focus groups and observational techniques. o Examples of analysis to be included: thematic analysis,

	framework analysis and constant comparative method. o This may be stand-alone qualitative research, or reported as part of a mixed methods intervention evaluation or process evaluation. Exclude if: o Open-ended questionnaire items are only qualitative data.
Country and language	Include if: o Full text is in English o OECD setting

Table 2: Examples of interpretative and descriptive themes within primary studies

	First-order construct (Participant quote)	Second-order construct (Author interpretation)
Interpretative theme	“People are just together. You’re never alone…It’s affected me a lot because I’m probably one of the only people in my school that has sickle cell so it’s like, there’s not really any people to like connect with or talk about it with. So when you come here it’s just really fun to talk to people about it or just even know that the people around you share the same reactions and altercations about it.” [CYP, SCD] (Gillard et al., 2016 p115)	Sense of belonging (Gillard et al., 2016)
Descriptive theme	Don’t know what happened to the first one...I thought it was me…I could never get in touch with her. [CYP, CF] (MacDonald et al., 2010 p2411)	Befriending – what’s not so good about it? (MacDonald et al., 2010)

CF = Cystic Fibrosis, SCD = Sickle Cell Disease.

Table 3: Reason for exclusion at full text screening: Review 2

Record	Reason for exclusion
Abramowitz S, Koenig LJ, Chandwani S, Orban L, Stein R, Lagrange R, et al. Characterizing social support: global and specific social support experiences of HIV-infected youth. AIDS Patient Care STDS. 2009;23(5):323-30.	Lack of qualitative analysis
Adams, M. A. (1976). A hospital play program: Helping children with serious illness. American Journal of Orthopsychiatry, 46, 416–424	Full text not retrieved
Algtewi EE, Owens J, Baker SR. Analysing people with head and neck cancers' use of online support groups. Cyberpsychology. 2015;9(4).	Older sample
Allison S, Baune BT, Roeger L, Coppin B, Bastiampillai T, Reed R. Youth consultation-liaison psychiatry: How can we improve outcomes for young people with chronic illness? Australian and New Zealand Journal of Psychiatry. 2013;47(7):613-6.	Lack of qualitative analysis
Amer K. Bibliotherapy: using fiction to help children in two populations discuss feelings. Pediatr Nurs. 1999;25(1):91-5.	Intervention not aiming to improve mental health
Amer K. Practice applications of research. Bibliotherapy: using fiction to help children in two populations discuss feelings. Pediatr Nurs. 1999;25(1):91-5 5p.	Intervention not aiming to improve mental health
Ångström-Brännström C, Dahlqvist V, Norberg A. Victor and the Dragon. Journal of Hospice & Palliative Nursing. 2013;15(8):464-70 7p.	No intervention focus
Anonymous. 2013 SYR Accepted Poster Abstracts. Int. 2013;23 Suppl:32-53.	Full text not retrieved
Anonymous. Making good connections. AIDS Action. 1993(22):2-3.	Older sample
Anonymous. Prevention programmes in residential settings. AIDS Health Promot Exch. 1994(4):1-2.	Full text not retrieved
Anonymous. Socio-behavioural research by WHO. Soc Afr SIDA. 1994;Lettre d'information.(3):6.	Not OECD country
Anonymous. Young people take action. AIDS Action. 1994(25):5.	Lack of qualitative analysis
Bacha, R., Pomeroy, E. C., & Gilbert, D. (1999). A psychoeducational group intervention for HIV-positive children: A pilot study. Health & Social Work, 24, 303–306.	Lack of qualitative analysis

Baerg, S. (2003). “Sometimes there just aren’t any words”: Using expressive therapy with adolescents living with cancer. Canadian Journal o f Counselling, 37, 65 -74.	No qualitative data collection
Baider, L, & De-Nour, A. K. (1989). Group therapy with adolescent cancer patients. Journal of Adolescent Health Care, 10, 35–38	No qualitative data collection
Baird J, Rehm RS, Hinds PS, Baggott C, Davies B. Do You Know My Child? Continuity of Nursing Care in the Pediatric Intensive Care Unit. Nursing Research. 2016;65(2):142-50.	Intervention not aiming to improve mental health
Balen 2000 Listening to Children with Cancer	Lack of qualitative analysis
Balen R, Fielding D, Lewis IJ. An activity week for children with cancer: who wants to go and why? Child Care Health Dev. 1998;24(2):169-77.	CYP do not all have LTC
Balfe M, Doyle F, Smith D, Sreenan S, Brugha R, Hevey D, et al. What's distressing about having type 1 diabetes? A qualitative study of young adults' perspectives. BMC Endocr Disord. 2013;13:25.	Intervention not aiming to improve mental health
Barlow J, Powell L, Cheshire A. The Training and Support Programme (involving basic massage) for parents of children with cerebral palsy: An implementation study. Journal of Bodywork and Movement Therapies. 2007;11(1):44-53.	Intervention not aiming to improve mental health
Barrera M, Damore-Petingola S, Fleming C, et al. (2006) Support and intervention groups for adolescents with cancer in two Ontario communities. Cancer 107: 1680–1685.	No qualitative data collection
Barrera M. Brief clinical report: procedural pain and anxiety management with mother and sibling as co-therapists. J Pediatr Psychol. 2000;25(2):117-21.	Lack of qualitative analysis
Barrera ME, Rykov MH, Doyle SL. The effects of interactive music therapy on hospitalized children with cancer: a pilot study. Psychooncology. 2002;11(5):379-88.	Lack of qualitative analysis
Baskin ML. A psychoeducational group intervention for adolescents diagnosed with sickle cell disease (SCD). Dissertation Abstracts International: Section B: The Sciences and Engineering. 2000;60(12-B):6353.	Lack of qualitative analysis
Basso R. A structured-fantasy group experience in a children's diabetic education program. Patient Education and Counseling. 1991;18(3):243-51.	Lack of qualitative analysis
Basso RV, Pelech WJ. A creative arts intervention for children with diabetes. Part 2: evaluation. J Psychosoc Nurs Ment Health	Lack of qualitative

Serv. 2008;46(12):25-8.	analysis
Battles HB, Wiener LS. STARBRIGHT World: Effects of an electronic network on the social environment of children with life-threatening illnesses. Children's Health Care. 2002;31(1):47-68.	Lack of qualitative analysis
Beck-Sague CM, Devieux J, Pinzon-Iregui MC, Lerebours-Nadal L, Abreu-Perez R, Bertrand R, et al. Disclosure of their HIV status to perinatally infected youth using the adapted Blasini disclosure model in Haiti and the Dominican Republic: preliminary results. Aids. 2015;29 Suppl 1:S91-8.	Not OECD country
Beresford B, Clarke S, Greco V. Referrers' use and views of specialist mental health services for deaf children and young people in England. J Ment Health. 2010;19(2):193-201.	No intervention focus
Bhana A, Mellins CA, Petersen I, Alicea S, Myeza N, Holst H, et al. The VUKA family program: Piloting a family-based psychosocial intervention to promote health and mental health among HIV infected early adolescents in South Africa. AIDS Care. 2014;26(1):1-11 p.	Not OECD country
Bhatta DN, Liabsuetrakul T. Design and feasibility of a social self-value intervention package to empower people living with HIV. AIDS care. 2016:1-7.	Older sample
Bouchard F, Landry M, Belles-Isles M, Gagnon J. A magical dream: a pilot project in animal-assisted therapy in pediatric oncology. Can Oncol Nurs J. 2004;14(1):14-7.	Lack of qualitative analysis
Bouzoukis CE. Fairy tales in the treatment of chronically-ill children. Dissertation Abstracts International Section A: Humanities and Social Sciences. 1999;60(6-A):1833.	Lack of qualitative analysis
Boyd, J.R. & Hunsberger, M. (1998). Chronically ill children coping with repeated hospitalizations: Their perceptions and suggested interventions. Journal of Pediatric Nursing, 13(6), 330-342.	No intervention focus
Breen LJ, Wildy H, Saggers S, Millsteed J, Raghavendra P. In search of wellness: allied health professionals' understandings of wellness in childhood disability services. Disabil Rehabil. 2011;33(10):862-71.	Intervention not aiming to improve mental health
Bricher G, Darbyshire P. 'I know my body, I've lived in it all my life': therapy experiences of young people with disabilities. Contemp Nurse. 2004;18(1-2):18-33.	Intervention not aiming to improve mental health
Brodsky W. Music therapy as an intervention for children with cancer in isolation rooms. Music Therapy. 1989;8(1):17-34.	Lack of qualitative

	analysis
Broome ME. Preparation of children for painful procedures. Pediatr Nurs. 1990;16(6):537-41.	No qualitative data collection
Brown 2013 Parenting a child with a traumatic brain injury: Experiences of parents and health professionals	No intervention focus
Cantrell MA, Matula C. The meaning of comfort for pediatric patients with cancer. Oncol Nurs Forum. 2009;36(6):E303-9.	Intervention not aiming to improve mental health
Capitulo KL. Music therapy to reduce pain and anxiety in children with cancer undergoing lumbar puncture: A randomized clinical trial. MCN: The American Journal of Maternal/Child Nursing. 2015;40(4):268.	No qualitative data collection
Carr SM, Smith IC, Simm R. Solution-focused brief therapy from the perspective of clients with long-term physical health conditions. Psychology Health & Medicine. 2014;19(4):384-91.	Older sample
Carr-Gregg, M., & Hampson, R. (1986). A new approach to the psychological care of adolescents with cancer. Medical Journal of Australia, 145,	Full text not retrieved
Caty S, Ellerton ML, Ritchie JA. Use of a projective technique to assess young children's appraisal and coping responses to a venipuncture. Journal of the Society of Pediatric Nurses. 1997;2(2):83-92.	CYP do not all have LTC
Céspedes-Knadle YM, Muñoz CE. Development of a Group Intervention for Teens With Type 1 Diabetes. Journal for Specialists in Group Work. 2011;36(4):278-95 18p.	Lack of qualitative analysis
Chaney D, Coates V, Shevlin M, Carson D, McDougall A, Long A. Diabetes education: what do adolescents want? J Clin Nurs. 2012;21(1-2):216-23.	Intervention not aiming to improve mental health
Chari U, Hirisave U, Appaji L. Exploring play therapy in pediatric oncology: a preliminary endeavour. Indian J Pediatr. 2013;80(4):303-8.	Not OECD country
Christie D, Hood D, Griffin A. Thinking, feeling and moving: drama and movement therapy as an adjunct to a multidisciplinary rehabilitation approach for chronic pain in two adolescent girls. Clin. 2006;11(4):569-77.	Lack of qualitative analysis
Christie D, Romano GM, Thompson R, Viner RM, Hindmarsh PC. Attitudes to psychological groups in a paediatric and adolescent diabetes service -- implications for service delivery. Pediatric Diabetes. 2008;9(4pt2):388-92 5p.	Intervention not aiming to improve mental health
Christie D, Thompson R, Sawtell M, Allen E, Cairns J, Smith F, et al. Structured, intensive education maximising engagement,	Intervention not aiming to

motivation and long-term change for children and young people with diabetes: a cluster randomised controlled trial with integral process and economic evaluation - the CASCADE study. Health Technology Assessment. 2014;18(8):1-202 p.	improve mental health
Clark, H. B., Ichinose, C. K., Meseck-Bushey, S., Perez, K. R., Hall, M. S., Gibertini, M., & Crowe, T. (1992). Peer support group for adolescent with chronic illness. Child Health Care, 21, 233–238.	No qualitative data collection
Clarke M, McConachie H, Price K, Wood P. Notes and discussion. Views of young people using augmentative and alternative communication systems. International Journal of Language & Communication Disorders. 2001;36(1):107-15 9p.	CYP do not all have LTC
Clarke M, McConachie H, Price K, Wood P. Views of young people using augmentative and alternative communication systems. International Journal of Language & Communication Disorders. 2001;36(1):107-15.	CYP do not all have LTC
Clausson E, Berg A. Family intervention sessions: one useful way to improve schoolchildren's mental health. J Fam Nurs. 2008;14(3):289-313.	CYP do not all have LTC
Clemente I. Clinicians' routine use of non-disclosure: prioritizing "protection" over the information needs of adolescents with cancer. Can J Nurs Res. 2007;39(4):19-34.	No intervention focus
CLIC Sargent. The New Normal	Lack of qualitative analysis
Cofer, D. H., & Nir, Y. (1975). Theme- focused group therapy on a pediatric ward. International Journal of Psychiatry in Medicine, 6, 541–550.	Full text not retrieved
Cohen E, Lacombe-Duncan A, Spalding K, MacInnis J, Nicholas D, Narayanan UG, et al. Integrated complex care coordination for children with medical complexity: a mixed-methods evaluation of tertiary care-community collaboration. BMC Health Serv Res. 2012;12:366.	No qualitative data collection
Colombini MI, Schivalocchi E. The impact of diabetes on adolescent development: The experiences of teenagers with diabetes attending a summer camp. Adolescent Psychiatry. 2013;3(3):245-51.	Full text not retrieved
Cooke L, Chung C, Grant M. Psychosocial care for adolescent and young adult hematopoietic cell transplant patients. J Psychosoc Oncol. 2011;29(4):394-414.	Intervention not aiming to improve mental health
Coulson N, Greenwood N. Families affected by childhood cancer: An analysis of the provision of social support within online support groups. Child: Care, Health and Development. 2012;38(6):870-7.	Intervention not aiming to improve mental health

Coulson, N. S. (2005). Receiving social support online: An analysis of a computer-mediated support group for individuals living with irritable bowel syndrome. CyberPsychology & Behavior, 8, 580-584	Intervention not aiming to improve mental health
Culpert TP, Kajander RL, Reaney JB. Biofeedback with children and adolescents: Clinical observations and patient perspectives. Journal of Developmental and Behavioral Pediatrics. 1996;17(5):342-50.	Lack of qualitative analysis
Dalberg T, Jacob-Files E, Carney PA, Meyrowitz J, Fromme EK, Thomas G. Pediatric oncology providers' perceptions of barriers and facilitators to early integration of pediatric palliative care. Pediatr Blood Cancer. 2013;60(11):1875-81.	Intervention not aiming to improve mental health
Daley BJ. Sponsorship for adolescents with diabetes. Health Soc Work. 1992;17(3):173-82.	Lack of qualitative analysis
David CL, Williamson K, Tilsley DWO. A small scale, qualitative focus group to investigate the psychosocial support needs of teenage young adult cancer patients undergoing radiotherapy in Wales. European Journal of Oncology Nursing. 2012;16(4):375-9.	No intervention focus
DeMaso DR, Gonzalez-Heydrich J, Erickson JD, Grimes VP, Strohecker C. The experience journal: a computer-based intervention for families facing congenital heart disease. J Am Acad Child Adolesc Psychiatry. 2000;39(6):727-34.	Lack of qualitative analysis
Dengler KA, Scarfe G, Redshaw S, Wilson V. The heart beads program. J Spec Pediatr Nurs. 2011;16(1):80-4.	No qualitative data collection
Doyle M. Peer Support and Mentorship in a US Rare Disease Community: Findings from the Cystinosis in Emerging Adulthood Study. Patient-Patient Centered Outcomes Research. 2015;8(1):65-73.	No intervention focus
Dragone 2002 Development and Evaluation of an Interactive CD-ROM for Children with Leukemia and Their Families1	Lack of qualitative analysis
Dvorak AL. Music Therapy Support Groups for Cancer Patients and Caregivers: A Mixed-Methods Approach. Canadian Journal of Music Therapy. 2015;21(1).	Older sample
Ebersohn L, Ferreira R. Coping in an HIV/AIDS-dominated context: teachers promoting resilience in schools. Health Educ Res. 2011;26(4):596-613.	Not OECD country
Ebrahimpour F, Najafi M, Sadeghi N. The design and development of a computer game on insulin injection. Electron Physician. 2014;6(2):845-55.	Not OECD country

Eide JM. Stress management for teens with type 1 diabetes. Dissertation Abstracts International: Section B: The Sciences and Engineering. 2013;74(1-B(E)):No Pagination Specified.	Full text not retrieved
Elmaci DT, Cevizci S. Dog-assisted therapies and activities in rehabilitation of children with cerebral palsy and physical and mental disabilities. Int J Environ Res Public Health. 2015;12(5):5046-60.	Lack of qualitative analysis
Elwell L, Grogan S, Coulson N. Adolescents living with cancer: the role of computer-mediated support groups. J Health Psychol. 2011;16(2):236-48.	CYP do not all have LTC
Enskar K, Carlsson M, Golsater M, Hamrin E. Symptom distress and life situation in adolescents with cancer. Cancer Nurs. 1997;20(1):23-33.	Intervention not aiming to improve mental health
Espinoza M, Baños RM, García-Palacios A, Botella C. Virtual reality in oncology patients with psychological interventions. Psicooncologia. 2013;10(2-3):247-61.	Foreign language
Evans S, Moieni M, Taub R, Subramanian SK, Tsao JC, Sternlieb B, et al. Iyengar yoga for young adults with rheumatoid arthritis: results from a mixed-methods pilot study. J Pain Symptom Manage. 2010;39(5):904-13.	Older sample
Ewing, L. J., Long, K., Rotindi, A., Howe, C., Bill, L., & Marsland, A. L. (2009). Brief report: a pilot study of a web-based resource for families of children with cancer. Journal of Pediatric Psychology, 34, 523–529.	Lack of qualitative analysis
Fagen, T. (1982). Music therapy in the treatment of anxiety and fear in terminal pediatric patients. Music Therap;', 2(1), 13-24.	No qualitative data collection
Feeney TJ, Ylvisaker M. Context-sensitive behavioral supports for young children with TBI: short-term effects and long-term outcome. J Head Trauma Rehabil. 2003;18(1):33-51.	Lack of qualitative analysis
Flicker S, Skinner H, Read S, Veinot T, McClelland A, Saulnier P, et al. Falling through the cracks of the big cities: who is meeting the needs of HIV-positive youth? Can J Public Health. 2005;96(4):308-12.	Intervention not aiming to improve mental health
Fotopoulos C. Cognitive Behavioural Therapy (CBT) for Sickle Cell Patients – Focus Groups Report. 2014.	Lack of qualitative analysis
Froehlich 1984 A Comparison of the Effect of Music Therapy and Medical Play Therapy on the Verbalization Behavior of Pediatric Patients	Lack of qualitative analysis
Galonski L. An exploration of clinicians' use of canine-assisted therapy with child and adolescent clients. Dissertation Abstracts	CYP do not all have LTC

International: Section B: The Sciences and Engineering. 2015;76(3-B(E)):No Pagination Specified.	
Gardner RM, Bird FL, Maguire H, Carreiro R, Abenaim N. Intensive positive behavior supports for adolescents with acquired brain injury: long-term outcomes in community settings. J Head Trauma Rehabil. 2003;18(1):52-74.	Lack of qualitative analysis
Gaulin NL. The experience of adolescents using online social networks to cope with their cancer: Exploring grouploop's discussion board and online support groups. Dissertation Abstracts International: Section B: The Sciences and Engineering. 2006;66(11-B):6270.	Lack of qualitative analysis
Gehl MB. Project caring: an intervention evaluation study of care coordination for children with chronic conditions from low-income families: UNIVERSITY OF PITTSBURGH; 1993.	CYP do not all have LTC
Gerskowitch C, Norman I, Rimes KA. Patients with medically unexplained physical symptoms experience of receiving treatment in a primary-care psychological therapies service: a qualitative study. Cognitive Behaviour Therapist. 2015;8.	Older sample
Gilboa A, Roginsky E. Examining the dyadic music therapy treatment (DUET): The case of a CP child and his mother. Nordic Journal of Music Therapy. 2010;19(2):103-32.	Intervention not aiming to improve mental health
Glatt L. An assessment of the clinical needs of females with type 1 diabetes and eating disorders. Dissertation Abstracts International: Section B: The Sciences and Engineering. 2013;74(6-B(E)):No Pagination Specified.	No intervention focus
Goldbeck L, Babka C. Development and evaluation of a multi-family psychoeducational program for cystic fibrosis. Patient Educ Couns. 2001;44(2):187-92.	No qualitative data collection
Goldenberg D, Payne LA, Hayes LP, Zeltzer LK, Tsao JC. Peer mentorship teaches social tools for pain self-management: A case study. Journal of Pain Management. 2013;6(1):61-8.	Lack of qualitative analysis
Gonzalez-Morkos B, Zavala O, Malogolowkin M, Kuperberg A. The teen impact experience: a webcast pilot project for teens with cancer and blood diseases. J Pediatr Oncol Nurs. 2014;31(5):272-6.	Lack of qualitative analysis
Goodwin 2005 The Meaning of Summer Camp Experiences to Youths With Disabilities	CYP do not all have LTC
Goodwin DL, Lieberman LJ, Johnston K, Leo J. Connecting through summer camp: Youth with visual impairments find a sense of community. Adapted Physical Activity Quarterly. 2011;28(1):40-55.	Intervention not aiming to improve mental health
Gossart-Walker, S., & Moss, N. E. (1998). Support groups for HIV-affected children. Journal of Child and Adolescent Group Therapy, 8, 55–69	Full text not retrieved

Gotte M, Kesting S, Winter C, Rosenbaum D, Boos J. Experience of barriers and motivations for physical activities and exercise during treatment of pediatric patients with cancer. Pediatr Blood Cancer. 2014;61(9):1632-7.	Intervention not aiming to improve mental health
Greco 2009 Deaf Children and Young People's Experiences of Using Specialist Mental Health Services	No intervention focus
Greene JA, Choudhry NK, Kilabuk E, Shrank WH. Online social networking by patients with diabetes: a qualitative evaluation of communication with Facebook. J Gen Intern Med. 2011;26(3): 287–92.	Intervention not aiming to improve mental health
Gregory J, Robling M, Bennert K, Channon S, Cohen D, Crowne E, et al. Development and evaluation by a cluster randomised trial of a psychosocial intervention in children and teenagers experiencing diabetes: the DEPICTED study. Health Technol Assess. 2011;15(29):1-202.	Intervention not aiming to improve mental health
Hackett J. Perceptions of Play and Leisure in Junior School Aged Children with Juvenile Idiopathic Arthritis: What are the Implications for Occupational Therapy? The British Journal of Occupational Therapy. 2003;66(7):303-10.	Intervention not aiming to improve mental health
Hammarberg K, Sartore G, Cann W, Fisher JR. Barriers and promoters of participation in facilitated peer support groups for carers of children with special needs. Scand J Caring Sci. 2014;28(4):775-83.	Intervention not aiming to improve mental health
Happ MB, Hoffman LA, DiVirgilio D, Higgins LW, Orenstein DM. Parent and child perceptions of a self-regulated, home-based exercise program for children with cystic fibrosis. Nursing Research. 2013;62(5):305-14.	Intervention not aiming to improve mental health
Hart R, Walton M. Magic as a therapeutic intervention to promote coping in hospitalized pediatric patients. Pediatr Nurs. 2010;36(1):11-6; quiz 7.	No qualitative data collection
Hartley S, Murira G, Mwangoma M, Carter J, Newton CR. Using community/researcher partnerships to develop a culturally relevant intervention for children with communication disabilities in Kenya. Disabil Rehabil. 2009;31(6):490-9.	Not OECD country
Hildenbrand AK, Clawson KJ, Alderfer MA, Marsac ML. Coping with pediatric cancer: strategies employed by children and their parents to manage cancer-related stressors during treatment. J Pediatr Oncol Nurs. 2011;28(6):344-54.	Intervention not aiming to improve mental health
Hilgard JR, LeBaron S. Relief of anxiety and pain in children and adolescents with cancer: Quantitative measures and clinical observations. International Journal of Clinical and Experimental Hypnosis. 1982;30(4):417-42.	Lack of qualitative analysis
Hinds 2005 End-of-Life Care Preferences of Pediatric Patients With Cancer	Intervention not aiming to improve mental health

Holland JC, Kelly BJ, Weinberger MI: Why psychosocial care is difficult to integrate into routine cancer care: Stigma is the elephant in the room. J Natl Compr Canc Netw 8:362-366, 2010	Full text not retrieved
Hollander SA. HIV/AIDS affected families: A challenge to health care professionals. Dissertation Abstracts International: Section B: The Sciences and Engineering. 1995;56(5-B):2845.	No intervention focus
Hopia H, Tomlinson PS, Paavilainen E, Astedt-Kurki P. Child in hospital: family experiences and expectations of how nurses can promote family health. J Clin Nurs. 2005;14(2):212-22.	No intervention focus
Houlahan KE, Branowicki PA, Mack JW, Dinning C, McCabe M. Can end of life care for the pediatric patient suffering with escalating and intractable symptoms be improved? J Pediatr Oncol Nurs. 2006;23(1):45-51.	No qualitative data collection
Hunt SM. Patterns of psychosocial functioning and mental health service utilization in children and adolescents with chronic health conditions or physical disabilities. Dissertation Abstracts International: Section B: The Sciences and Engineering. 2009;70(5-B):3173.	No intervention focus
Hunter, H. L., Rosnov, D. L., Koontz, D., & Roberts, M. C. (2006). Camping programs for children with chronic illness as a modality for recreation, treatment, and evaluation: An example of a mission-based program evaluation of a diabetes camp. Journal of Clinical Psychology in Medical Settings, 13, 67-80.	No qualitative data collection
Hutchinson E, Hall C. A phenomenological exploration of the patient learning J experiences of 16-19 year-old women accessing a young people's rheumatology service in the UK. Journal of Research in Nursing. 2007;12(5):521-33.	No intervention focus
Huynh E, Rand D, McNeill C, Brown S, Senechal M, Wicklow B, et al. Beating Diabetes Together: A Mixed-Methods Analysis of a Feasibility Study of Intensive Lifestyle Intervention for Youth with Type 2 Diabetes. Can. 2015;39(6):484-90.	Intervention not aiming to improve mental health
Iles N, Lowton K. Young people with cystic fibrosis' concerns for their future: When and how should concerns be addressed, and by whom? Journal of Interprofessional Care. 2008;22(4):436-8.	Lack of qualitative analysis
Johnson RL, Botwinick G, Sell RL, Martinez J, Siciliano C, Friedman LB, et al. The utilization of treatment and case management services by HIV-infected youth. J Adolesc Health. 2003;33(2 Suppl):31-8.	Lack of qualitative analysis
Johnson, K. B., Ravert, R. D., & Everton, A. (2001). Hopkins teen central: Assessment of an Internet-based support system for children with cystic fibrosis. Pediatrics, 107, 1–8.	No qualitative data collection
Jones EM. The efficacy of intensive individual play therapy for children diagnosed with insulin-dependent diabetes mellitus.	Lack of qualitative

Dissertation Abstracts International Section A: Humanities and Social Sciences. 2001;61(10-A):3907.	analysis
Jones VM. Mask making as art therapy with pediatric oncology patients. Dissertation Abstracts International: Section B: The Sciences and Engineering. 1997;57(8-B):5330.	Lack of qualitative analysis
Kaven MC. Moving forward: Psychotherapy with a youth after brain injury. Pediatric neuropsychology case studies: From the exceptional to the commonplace. New York, NY: Springer Science + Business Media; US; 2008. p. 97-107.	No qualitative data collection
Keener J. Youthworks: Curriculum development for a psychosocial support group for preteens with cancer. Dissertation Abstracts International: Section B: The Sciences and Engineering. 2008;69(5-B):3269.	No qualitative data collection
Kendall L, Sloper P, Lewin RJ, Parsons JM. The views of young people with congenital cardiac disease on designing the services for their treatment. Cardiol Young. 2003;13(1):11-9.	No intervention focus
Kiernan 2005 Children's voices: qualitative data from the 'Barretstown studies'	No qualitative data collection
Kim B, Gillham DM. The experience of young adult cancer patients described through online narratives. Cancer Nurs. 2013;36(5):377-84.	Intervention not aiming to improve mental health
Klein T, Gelderblom GJ, de Witte L, Vanstipelen S. Evaluation of short term effects of the IROMEC robotic toy for children with developmental disabilities. IEEE Int. 2011;2011:5975406.	IQ of sample below 70
Klinkenberg S, Aalbers MW, Vles JS, Cornips EM, Rijkers K, Leenen L, et al. Vagus nerve stimulation in children with intractable epilepsy: a randomized controlled trial. Dev Med Child Neurol. 2012;54(9):855-61.	Lack of qualitative analysis
Kmita (2002) Psychosocial intervention in the process of empowering families with children living with HIV/AIDS–a descriptive study. AIDS Care. 2002;14(2):279	Lack of qualitative analysis
Kmita G, Baranska M, Niemiec T. Psychosocial intervention in the process of empowering families with children living with HIV/AIDS -- a descriptive study. AIDS Care. 2002;14(2):279-84 6p.	CYP do not all have LTC
Knapp D, Devine MA, Dawson S, Piatt J. Examining Perceptions of Social Acceptance and Quality of Life of Pediatric Campers with Physical Disabilities. Children's Health Care. 2015;44(1):1-16 p.	Intervention not aiming to improve mental health
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Thomas C. Parent experiences in using positive behavior support to reduce challenging behavior in children with severe disabilities: A qualitative case study. Dissertation Abstracts International Section A: Humanities and Social Sciences. 2011;71(8-A):2849.	CYP do not all have LTC
Tong A, Gow K, Wong G, Henning P, Carroll R. Patient perspectives of a young adult renal clinic: a mixed-methods evaluation. Nephrology. 2015;20(5):352-9.	Intervention not aiming to improve mental health
Tong A, Jones J, Speerin R, Filocamo K, Chaitow J, Singh-Grewal D. Consumer Perspectives on Pediatric Rheumatology Care and Service Delivery A Qualitative Study. Jcr-Journal of Clinical Rheumatology. 2013;19(5):234-40.	No intervention focus
Tonkin-Crine S, Bishop FL, Ellis M, et al. Exploring patients’ views of a cognitive behavioral therapy-based website for the self-management of irritable bowel syndrome symptoms. J Med Internet Res. 2013;15:e190.	Older sample
Trollvik A, Ringsberg KC, Silen C. Children's experiences of a participation approach to asthma education. J Clin Nurs. 2013;22(7-8):996-1004.	No intervention focus
Tsiantis J, Anastasopoulos D, Meyer M, Panitz D, Ladis V, Platokouki N, et al. A multi-level intervention approach for care of HIV-positive haemophiliac and thalassaemic patients and their families. AIDS Care. 1990;2(3):253-66.	Lack of qualitative analysis
Urman ML. Development and evaluation of a group treatment for enhancing the self-esteem of adolescent girls with spina bifida. Dissertation Abstracts International: Section B: The Sciences and Engineering. 2002;62(7-B):3391.	Lack of qualitative analysis
Urowitz S, Wiljer D, Dupak K, Kuehner Z, Leonard K, Lovrics E, et al. Improving diabetes management with a patient portal: Qualitative study of a diabetes self-management portal. Journal of Medical Internet Research. 2012;14(6).	Intervention not aiming to improve mental health
Vessey JA, O'Neill KM. Helping students with disabilities better address teasing and bullying situations: a MASNRN study. J Sch Nurs. 2011;27(2):139-48.	CYP do not all have LTC
Villadsen KW, Blix C, Boisen KA. More than a break: the impact of a social-pedagogical intervention during young persons' long-term hospital admission--a qualitative study. Int J Adolesc Med Health. 2015;27(1):19-24.	CYP do not all have LTC
Waller H, Eiser C, Heller S, Knowles J, Price K. Adolescents' and their parents' views on the acceptability and design of a new diabetes education programme: a focus group analysis. Child Care Health Dev. 2005;31(3):283-9.	Intervention not aiming to improve mental health

Warady, B. A., Carr, B., Hellerstein, S., & Alon, U. (1992). Residential summer camp for children with end-stage renal disease. Child Nephrology and Urology, 12, 212–215.	Full text not retrieved
Wenkus M, Rittenhouse B, Dancer J. Classroom management programs for deaf children in state residential and large public schools. Percept Mot Skills. 1999;89(3 Pt 2):1211-4.	Intervention not aiming to improve mental health
Westergren T, Fegran L, Nilsen T, Haraldstad K, Kittang OB, Berntsen S. Active play exercise intervention in children with asthma: a PILOT STUDY. BMJ Open. 2016;6(1):e009721.	Intervention not aiming to improve mental health
Whitehead-Pleaux AM, Zebrowski N, Baryza MJ, Sheridan RL. Exploring the effects of music therapy on pediatric pain: phase 1. J Music Ther. 2007;44(3):217-41.	Lack of qualitative analysis
Wiener 2008 How I Wish to be Remembered: The Use of an Advance Care Planning Document in Adolescent and Young Adult Populations	Lack of qualitative analysis
Wiener L et al (2011) ShopTalk: a pilot study of the feasibility and utility of a therapeutic board game for youth living with cancer. Supportive Care in Cancer 19(7):1049–1054	No qualitative data collection
Williams LK, McCarthy MC. Parent perceptions of managing child behavioural side-effects of cancer treatment: a qualitative study. Child Care Health Dev. 2015;41(4):611-9.	Intervention not aiming to improve mental health
Wolitzky K, Fivush R, Zimand E, Hodges L, Rothbaum BO. Effectiveness of virtual reality distraction during a painful medical procedure in pediatric oncology patients. Psychology & Health. 2005;20(6):817-24.	Lack of qualitative analysis
Woods 2012 Feasibility and consumer satisfaction ratings following an intervention for families who have a child with acquired brain injury	Lack of qualitative analysis
Wright B, Walker R, Holwell A, Gentili N, Barker M, Rhys-Jones S, et al. A new dedicated mental health service for deaf children and adolescents. Advances in Mental Health. 2012;11(1):95-105.	No qualitative data collection
Wu KN, Lieber E, Siddarth P, Smith K, Sankar R, Caplan R. Dealing with epilepsy: parents speak up. Epilepsy Behav. 2008;13(1):131-8.	No intervention focus
Wu LM, Chiou SS, Sheen JM, Lin PC, Liao YM, Chen HM, et al. Evaluating the acceptability and efficacy of a psycho-educational intervention for coping and symptom management by children with cancer: a randomized controlled study. J Adv Nurs. 2014;70(7):1653-62.	Not OECD country

Wu, Y., Prout, K., Roberts, M., Parikshak, S., & Amylon, M. (2011). Assessing experiences of children who attended a camp for children with cancer and their siblings: A preliminary study. Child & Youth Care Forum, 40(2), 121–133. http://dx.doi.org/ 10.1007/s10566-010-9123-5.	No qualitative data collection
Wysocki 1997 Social Validity of Support Group and Behavior Therapy Interventions for Families of Adolescents with Insulin-Dependent Diabetes Mellitus1	Lack of qualitative analysis
Ylven R, Granlund M. Identifying and building on family strength: A thematic analysis. Infants & Young Children. 2009;22(4):253-63.	CYP do not all have LTC
Yoon Irons J, Kuipers K, Petocz P. Exploring the health benefits singing for young people with cystic fibrosis. International Journal of Therapy & Rehabilitation. 2013;20(3):144-53 10p.	Lack of qualitative analysis
Zack J, Jacobs CP, Keenan PM, Harney K, Woods ER, Colin AA, et al. Perspectives of patients with cystic fibrosis on preventive counseling and transition to adult care. Pediatr Pulmonol. 2003;36(5):376-83.	Intervention not aiming to improve mental health
Zangen T, Ciarla C, Zangen S, Di Lorenzo C, Flores AF, Cocjin J, et al. Gastrointestinal motility and sensory abnormalities may contribute to food refusal in medically fragile toddlers. J Pediatr Gastroenterol Nutr. 2003;37(3):287-93.	CYP do not all have LTC
Zarabi MC. The impact of inflammatory bowel disease on student functioning: A resource guide for students, parents, and school personnel. Dissertation Abstracts International: Section B: The Sciences and Engineering. 2005;66(6-B):3431.	No qualitative data collection
Zebrack B, Butler M. Context for understanding psychosocial outcomes and behavior among adolescents and young adults with cancer. JNCCN Journal of the National Comprehensive Cancer Network. 2012;10(9):1151-6.	No qualitative data collection
Zebrack B, Chesler MA, Kaplan S. To foster healing among adolescents and young adults with cancer: what helps? What hurts? Support Care Cancer. 2010;18(1):131-5.	Intervention not aiming to improve mental health
Zeltzer LK, Dolgin MJ, LeBaron S, LeBaron C. A randomized, controlled study of behavioral intervention for chemotherapy distress in children with cancer. Pediatrics. 1991;88(1):34-42.	Lack of qualitative analysis

Table 4: Key characteristics of included studies

First author, date	Country	Publication type	Study focus	Intervention type	Qualitative data collection method	Total sample size (N)	Details of participants providing qualitative data (N, who, % female, mean age years (SD)	Type of qualitative data analysis
Ayers (2011)	United Kingdom	JAP	Views about interventions received	Inhaled nitrous oxide, Play therapy, Parent support	Semi-structured interviews	28	14 White-European CYP with **Cystic Fibrosis**, 64.3% f, 12.4 years (range 7-15), 14 Parents, 78.6 f, 41.5 years (NR)	Systematic thematic analysis(Boyatzis, 1998)

First author, date	Country	Publication type	Study focus	Intervention type	Qualitative data collection method	Total sample size (N)	Details of participants providing qualitative data (N, who, % female, mean age years (SD)	Type of qualitative data analysis
Barlow (1999)	United Kingdom	JAP	Views on intervention in development	Psycho-educational	Five focus groups and two individual interviews	30	10 CYP with **Juvenile Arthritis**, 50 f, (range 8-15 years); 13 Parents, 69.2% f ; 7 Health professionals	Framework analysis
Barnetz (2012)	Israel	JAP	Views about intervention received	Mentoring	Semi-structured interviews, documented in writing during the interview.	24	24 CYP with **Type 1 Diabetes**, 46.9% f, 14 years (2.36)	Inductive content analysis based on grounded theory
Barnfather (2011) Stewart (2011b)	Canada	JAP	Mixed methods intervention evaluation	Online peer support (with Peer Mentors)	Online discussion transcripts; peer mentor field notes and interviews; CYP interviews	27	22 CYP with LTC (50% **Cerebral Palsy**, 50% **Spina Bifida**) , 45.5% f, 14.6 years (1.6); 5 peer mentors (40% Cerebral Palsy, 60% Spina Bifida) 60 f	Inductive thematic analysis(Kvale, 1996)

First author, date	Country	Publication type	Study focus	Intervention type	Qualitative data collection method	Total sample size (N)	Details of participants providing qualitative data (N, who, % female, mean age years (SD)	Type of qualitative data analysis
Barry (2010)	Australia	JAP	RCT evaluating intervention with qualitative component	Music therapy	CYP interviews, parent/staff questionnaires, therapist-researcher reflexive journal	45	11 CYP with **Cancer**, 50% f, Median age: 8 years (median); 11 Parents; 1 Music Therapy Researcher; 11 Treatment Staff; 11 Planning Staff	Thematic analysis based on modified grounded theory process(Amir, 2005)
Baruch (2010)	USA	D	Views about intervention received	Narrative/ Psychosocial support/Reward programme	Interviews, focus groups and surveys	29	6 CYP with **Cancer**, NR, 12.7 years (range 10-17); 8 Parents, 75% f, 36 years (range 31-45); 9 Practitioners; 6 Bead artists, NR, 21 years+	Qualitative descriptive methods: Inductive content analysis.
Bignall (2015)	USA	JAP	RCT evaluating intervention with qualitative component	Relaxation (Breathing)	Interviews after visits one and two.	30	15 African American CYP with **Asthma**, 66.7% f, 15.53 years (1.5)	Thematic analysis

First author, date	Country	Publication type	Study focus	Intervention type	Qualitative data collection method	Total sample size (N)	Details of participants providing qualitative data (N, who, % female, mean age years (SD)	Type of qualitative data analysis
Bluebond-Langer (1991)	USA	JAP	Views about intervention received.	Camp	CYP interviews, parent questionnaires and observations	50	50 CYP with **Cancer**, 42% f, 12 years (range 7-16 years)	Ethnography. Each transcript was independently coded (code book designed by the authors)
Brodeur (2005)	USA	D	Views about intervention received	Family art therapy	Semi-structured interviews	25	25 Total, 56.7% f, range 4-45 years 9 CYP with LTC; 13 Parents (9 mothers, 4 fathers); 3 Siblings	Interpretative phenomenological analysis
Brothers (2014)	USA	JAP	Views about intervention received	Group intervention/ Group therapy	Two open-ended items [from Session evaluation forms], three intervention deliverer interviews	25	22 female CYP with **HIV**, 0.55 years (16-24 years); 3 Intervention deliverers	Thematic analysis

First author, date	Country	Publication type	Study focus	Intervention type	Qualitative data collection method	Total sample size (N)	Details of participants providing qualitative data (N, who, % female, mean age years (SD)	Type of qualitative data analysis
Bultas (2015)	USA	JAP	Mixed methods intervention evaluation	Camp	CYP Photovoice interviews; parent open-ended survey questions.	50	50 CYP with **CHD**-Parent dyads, NR, range 8-15 years	Qualitative description. Non abstract/ interpretive, low inference, straight forward description of phenomena
Burns (2010)	USA	JAP	Views about intervention received	Music therapy	Interview	7	7 Parents of CYP with **Cancer**, 57.14% f, 16 years (range 13-21 years)	Colaizzi's empirical phenomenological approach(Colaizzi, 1978)
Campbell (2010)	United Kingdom	JAP	Views about intervention received	Group work	Interviews (telephone or in person during clinic appointment)	6	6 African Adolescents with **HIV**, 50% f, range 13-15 years	Thematic analysis

First author, date	Country	Publication type	Study focus	Intervention type	Qualitative data collection method	Total sample size (N)	Details of participants providing qualitative data (N, who, % female, mean age years (SD)	Type of qualitative data analysis
Curle (2005)	United Kingdom	JAP	Views about intervention received	Group therapy	Interviews semi-structured	27	11 White Children with LTC, 45.5% f, range 7-12 years; 14 Parents, 71.4% f, NR, 2 Siblings, 50 f, NR	Grounded Theory(Strauss & Corbin, 1990)
Dennison (2010)	United Kingdom	JAP	RCT evaluating intervention with qualitative component	CBT, psycho-education	Telephone interviews	32	16 White-British CYP with **CFS**, 62.5% f, 19.9 years (range 16-24); 16 Parents, 87.5 f, NR	Inductive thematic analysis
Desai (2014)	USA	JAP	Views about intervention received	Camp	Participant generated photography and semi-structured interviews	13	13 CYP with **CHD**, 38.46% f, 12.7 years (range 9-16)	Thematic analysis: Highlighting approach(Van Manen)

First author, date	Country	Publication type	Study focus	Intervention type	Qualitative data collection method	Total sample size (N)	Details of participants providing qualitative data (N, who, % female, mean age years (SD)	Type of qualitative data analysis
Docherty (2013)	USA	JAP	Views about intervention received	Music therapy	Unstructured qualitative interviews	16	16 Parents of CYP with **Cance**r, 87.5% f, 44.5 years (range 30-51)	Adaptation of Colaizzi's Phenomenological method of analysis(Colaizzi, 1978)
Fair (2012)	USA	JAP	Views about intervention received	Creative writing (Group)	Interviews	32	7 Adolescents with **HIV**, NR, 16 years (range 13-20); 4 Carers, 50% f, 55.3 years (range 45-71); 5 Group leaders, NR, 32 years (range 26-50)	Grounded Theory
Gan (2010)	USA	JAP	Views about intervention received	Family intervention/ therapy	Questionnaires and semi-structured interviews with family members and clinicians.	25	8 Adolescents with **ABI**, 37.5% f, 14.6 years (2.1); 14 Family members (9 parents, 1 partner, 4 siblings); 3 Clinicians, NR details	Content analysis

First author, date	Country	Publication type	Study focus	Intervention type	Qualitative data collection method	Total sample size (N)	Details of participants providing qualitative data (N, who, % female, mean age years (SD)	Type of qualitative data analysis
Gaysynsky (2015)	USA	JAP	Views about intervention received	Online support group	Online posts and comments transcripts from March 1st 2011 to July 1st 2012	43	43 CYP with **HIV**, 34.9% f, range 18-27 years.	Directed content analysis
Gillard (2011)	USA	JAP	Views about intervention received	Camp	In 2007: Camper focus groups, staff interviews and informal observations, interviews with former campers. In 2008: Formal and informal interviews with campers and staff, participant observations, and artefact reviews.	51	36 CYP with **HIV**, NR, range 7-19 years; 15 Staff, Other details NR	Grounded Theory as outlined by Strauss and Corbin (1998).(Strauss & Corbin, 1998) Analysis using the constant comparison method

First author, date	Country	Publication type	Study focus	Intervention type	Qualitative data collection method	Total sample size (N)	Details of participants providing qualitative data (N, who, % female, mean age years (SD)	Type of qualitative data analysis
Gillard (2013)	USA	JAP	Views about intervention received	Camp	Semi-structured interviews with campers and junior counsellors, observations. Focus groups with staff and 12 campers.	24	10 CYP with **Cancer**, NR, range 12-14 years; 4 Junior Counsellors, NR, range 18-20 years; 10 Staff	Constant comparison method
Gillard (2016)	USA	JAP	Views about intervention received	Camp	Video interviews	24	24 CYP with LTC, 70.83% f, 15 years (0.46).	Interpretative phenomenological analysis

First author, date	Country	Publication type	Study focus	Intervention type	Qualitative data collection method	Total sample size (N)	Details of participants providing qualitative data (N, who, % female, mean age years (SD)	Type of qualitative data analysis
Griffiths (2015)	United Kingdom	JAP	Views about intervention before and after received	Online support group	Pre-intervention focus groups. Views posted in forum during intervention. Post-intervention focus groups. Analysis of forum messages	12	12 CYP with **Cancer**, 58.30% f, 21.08 years (4.15)	Inductive thematic analysis(Braun & Clarke, 2006)
Hosek (2012)	USA	JAP	Views about intervention in development	Secondary prevention	Focus groups	17	17 female CYP with **HIV**, 21 years (range 17-24)	Thematic analysis
Jaser (2014)	USA	JAP	RCT evaluating intervention with qualitative component	Positive affirmation	Semi-structured interviews	37	20 Adolescents with **Type 1 Diabetes**, 60% f, 15.3 years (1.4); 17 Parents, 83.3 f	Content analysis

First author, date	Country	Publication type	Study focus	Intervention type	Qualitative data collection method	Total sample size (N)	Details of participants providing qualitative data (N, who, % female, mean age years (SD)	Type of qualitative data analysis
Kashikar-Zuck (2016)	USA	JAP	Mixed methods intervention evaluation	CBT + Neuromuscular exercise training	Interview	17	17 Adolescents with **JFM**, 100% f, 16(2.15)	Thematic analysis
Kirk (2016)	United Kingdom	JAP	Views about intervention received	Online support group	Website posts, Observational notes	279	97 CYP with **CF**; 182 Parents	Inductive grounded theory
(Lewis (2016)	Australia	JAP	Mixed methods intervention evaluation	Peer support	Focus groups, One-to-one interviews with coordinators	32	4 Adolescents with LTC (new members), 100% f, 12-17 years; 4 Adolescents with LTC (established members), 50% f, 17-23 years; 19 Parents of new members, 84.2% f; 5 Co-ordinators, 100 f	Thematic analysis

First author, date	Country	Publication type	Study focus	Intervention type	Qualitative data collection method	Total sample size (N)	Details of participants providing qualitative data (N, who, % female, mean age years (SD)	Type of qualitative data analysis
MacDonald (2010)	United Kingdom	JAP	Views about intervention received	Befriending programme	Semi-structured interviews, focus group	14	5 CYP with **Cystic Fibrosis**, NR, 13.4(range 8-18); 5 Parents; 4 Practitioners; 3 Befrienders	'Framework' model was used to build a matrix of themes and codes from the four sets of data
Marsac (2012)	USA	JAP	Views about intervention before and after received	Coping strategies	Semi-structured and cognitive interviews	30	15 CYP with **Cancer**, 46.7% f, 8.8 years (1.7); 15 Parents, 80 f, NR	Thematic analysis assumed
Masuda (2013)	Canada	JAP	Views about intervention before and after received	Online support	Individual interviews (face to face, telephone), group interview, open-ended survey questions	27	14 CYP with **Asthma and Life threatening allergies**, NR, 12-15 years 8 parents 5 peer mentors	Framework analysis

First author, date	Country	Publication type	Study focus	Intervention type	Qualitative data collection method	Total sample size (N)	Details of participants providing qualitative data (N, who, % female, mean age years (SD)	Type of qualitative data analysis
Moola (2015)	Canada	JAP	Views about intervention received	Camp	Semi-structured interviews	15	15 CYP with **CHD**, 60% f, range 9-16 years	Interpretative phenomenological analysis
Muskat (2016)	Canada	JAP	Views about intervention received	Support group	Semi-structured interviews	25	16 CYP with **HIV**, 37.5% f, Range 11-18 years; 9 Caregivers, 88.9 f, NR	McCracken's "Long Interview" method of qualitative data analysis(McCracken, 1988)
Nicholas (2007)	Canada	JAP	Views about intervention received	Online games, education and peer support network	Ethnographic semi-structured interviews	19	9 CYP with LTC, 22.2% f, 11.3 years (3.42); 7 family caregivers; 3 Health care providers	Interviews were audio-recorded, transcribed verbatim and subjected to theme generation

First author, date	Country	Publication type	Study focus	Intervention type	Qualitative data collection method	Total sample size (N)	Details of participants providing qualitative data (N, who, % female, mean age years (SD)	Type of qualitative data analysis
Nicholas (2009)	Canada	JAP	Mixed methods intervention evaluation	Asthma education delivered at summer camp	Semi-structured interviews	22	22 CYP with **Asthma**, 31.81% f, range 7-15 years	Transcripts were subjected to code identification, category development, and theme generation
Nicholas (2012)	Canada	JAP	Mixed methods intervention evaluation	Online education and support	Interviews: Long interview approach (McCracken, 1988)	15	15 CYP with **Type 1 diabetes** in intervention group, 14.5% f, range 12-17 years	Transcripts were content analysed and themes were generated
Nieto (2015)	Spain	JAP	Views about intervention before and after received	Online psychoeducation	Semi-structured, family interviews (face-to-face or by videoconference)	15	15 CYP with **FAP**, 60, Median age 11(range 9-14) and their Parents	Inductive content analysis

First author, date	Country	Publication type	Study focus	Intervention type	Qualitative data collection method	Total sample size (N)	Details of participants providing qualitative data (N, who, % female, mean age years (SD)	Type of qualitative data analysis
Nilsson (2009)	Sweden	JAP	Mixed methods intervention evaluation	Game	Semi-structured interviews	21	21 CYP with **Cancer**, 33.3% f, median age 11 years (range 5-18)	Content analysis. The meaning units were subsequently abstracted to categories and eventually abstracted to themes(Graneheim & Lundman, 2004)
O'Callaghan (2011)	Australia	JAP	Views about intervention received	Music/Music therapy	Semi-structured interviews	54	26 CYP with **Cancer**, 34.5% f, median (25th-75th percentile) 7.5 years (range 4.6-8.2); 28 Parents, 82.1 f, NR	Grounded theory: Comparative analytical process
O'Callaghan (2012)	Australia	JAP	Views about intervention received	Music therapy	Semi-structured interviews	12	12 CYP with **Cancer**, 58.33% f, 21 years (2.7)	Grounded theory and thematic analysis

First author, date	Country	Publication type	Study focus	Intervention type	Qualitative data collection method	Total sample size (N)	Details of participants providing qualitative data (N, who, % female, mean age years (SD)	Type of qualitative data analysis
O'Callaghan (2013)	Australia	JAP	Views about interventions delivered	Music/Music therapy	Semi-structured focus groups, therapists' written reflections	4	4 female Music therapists, NR	Grounded theory and thematic analysis
Reme (2013)	United Kingdom	JAP	Mixed methods intervention evaluation	Lightening Process	Semi-structured telephone interviews	12	9 CYP with **CFS**, 88.89% f, range 14-26 years; 3 Mothers, NR	Inductive thematic analysis
Romero (2014)	USA	D	Views about intervention received	Online support, social networking and education Site	Posts on social networking (intervention) site	74	74 CYP with **Cystic Fibrosis**, 71.6% f, 14.53 years (2.06)	Deductive thematic content analysis(Boyatzis, 1998)
Serlachius (2012)	Australia	JAP	Views about intervention in development	Coping skills	Semi-structured focus groups	13	13 Adolescents with **Type 1 Diabetes**, 30.77% f, 15.4 years (1.7)	Deductive thematic analysis

First author, date	Country	Publication type	Study focus	Intervention type	Qualitative data collection method	Total sample size (N)	Details of participants providing qualitative data (N, who, % female, mean age years (SD)	Type of qualitative data analysis
Shrimpton (2013)	Australia	JAP	Views about intervention received	Creative therapy/ Narrative therapy	Semi-structured interviews	10	40 Parents of CYP with **Cancer**	Thematic analysis
Sibinga (2011)	USA	JAP	Mixed methods intervention evaluation	Mindfulness-based stress reduction	Interviews	5	5 CYP with **HIV**, 80% f, 17 years (range 13-21)	Constant comparative method and content analysis
Stewart (2011a)	Canada	JAP	Mixed methods intervention evaluation	Games and online peer support	Individual telephone interviews	55	20 CYP with **Asthma and/or Severe Allergies**, NR, 8.64 years (1.06); 35 Parents	Constant comparative content analysis
Stewart (2013a;2013 b)	Canada	JAP	Mixed methods intervention evaluation	Games and online peer support	Session recordings, participant emails, individual and group interviews	57	27 CYP with **Asthma and Severe Allergies** (63%) or **Severe Allergies only**, NR, range 7-11 years; 25 Parents; 5 Peer Mentors	Thematic content analysis

First author, date	Country	Publication type	Study focus	Intervention type	Qualitative data collection method	Total sample size (N)	Details of participants providing qualitative data (N, who, % female, mean age years (SD)	Type of qualitative data analysis
Stinson (2008)	Canada	JAP	Views about intervention in development	Online self-management /education programme	Individual interviews and focus groups	36	36 CYP with **JIA**, 66.7% f, 15.1 years (2.1)	Thematic analysis
Stinson (2010)	Canada	JAP	Views about in development	Online support	Semi-structured interviews and observations	38	19 CYP with **JIA**, 74% f, 15.7 years (1.5) 19 Parents, 63 f, 53% 40-49 years	Content analysis
Tiemens (2007)	Canada	JAP	Mixed methods intervention evaluation	Camp	Focus groups	7	4 CYP with **craniofacial difference**, 100% f, 16.2 years (14-18); 3 parents	Constant comparative method(Vaughn et al., 1996)
Weekes (1993)	USA	JAP	Mixed methods intervention evaluation	Hand-holding	Observations and semi-structured interviews	20	10 CYP with **Cancer**, 50% f, 15.7 years (range 12-18); 10 CYP with **Renal Failure**, 50% f, 14.8 years (range 11-19)	Constant comparative techniques from grounded theory methodology.

First author, date	Country	Publication type	Study focus	Intervention type	Qualitative data collection method	Total sample size (N)	Details of participants providing qualitative data (N, who, % female, mean age years (SD)	Type of qualitative data analysis
White (2014;2016)	Canada	D, JAP	Views about intervention received	Camp	Semi-structured interviews	9	9 Parents of CYP with **CHD**, 88.9% f, 42 years (range 32-51)	Thematic analysis(Braun & Clarke, 2006)
Whittemore (2010)	USA	JAP	Views about intervention before and after received	Internet coping skills training program	Focus groups, think-aloud process, and the survey	13	13 Adolescents with **Type 1 Diabetes**, 40% f, 14 years (1.15); NR Parents	Content analysis method
Wolf Bordonaro (2005)	USA	D	Mixed methods intervention evaluation	Art therapy	Ethnographic research techniques	3	3 female CYP with **SCD**, Range 6-9 years	Ethnographic analysis

First author, date	Country	Publication type	Study focus	Intervention type	Qualitative data collection method	Total sample size (N)	Details of participants providing qualitative data (N, who, % female, mean age years (SD)	Type of qualitative data analysis
Wright (2004)	USA	JAP	Views about intervention received	Physical activity	Documentation of student progress structured interviews, case-specific questions, informal follow up interviews	26	7 CYP with **Cerebral Palsy**, 14.3% f ,range 4-11 years; 4 female Practitioners, NR; 5 Parents, 80 f, NR	Inductive analysis and constant comparison

Key: ABI = Acquired Brain Injury, CFS = Chronic Fatigue Syndrome, CHD = Congenital Heart Disease, D = Dissertation, FAP = Functional Abdominal Pain, JFM = Juvenile Fibromyalgia, JIA = Juvenile Idiopathic Arthritis, JAP = Journal Article Peer-Reviewed, NR = Not Reported, RCT = Randomised Control Trials, SD = Standard Deviation, SCD = Sickle Cell Disease

Table 5: Description of interventions

First author, Date	Participants	Mental health target of intervention	Other targets of intervention	Intervention name[a]	Intervention category	Site of intervention	Delivered by	Structure
Ayers (2011)	14 CYP with **Cystic Fibrosis**	Anxiety, distress	NA	Inhaled nitrous oxide, Play therapy, Parent support	NA	NR	NR	NR
Barlow (1999)	10 CYP with **Juvenile Arthritis**, 13 Parents, 7 Health professionals	Emotional impact of JA	LTC knowledge, beliefs and behaviour	Psychoeducational interventions	Psychoeducational	NA	NA	NA
Barnetz (2012)	32 CYP with **Type 1 Diabetes**	Acceptance and acknowledgment of diabetes, development of coping skills	Diabetes self-management	Sponsorship for Adolescents with Diabetes	Mentoring	Public places	Mentors: young adults with diabetes (20 and 30 years)	52 2-hour sessions held weekly
Barnfather (2011) Stewart (2011b)	22 CYP **Cerebral Palsy** (50%), or **Spina Bifida** (50%)	Emotional support, coping with stress of condition	Social support and LTC outcomes	Computer mediated support	Computer support group (with peer mentors)	Computer mediated.	5 peer mentors (2 CP, 3 SB). 2 Psychologists advised	25 1-1.5 hour sessions held weekly

First author, Date	Participants	Mental health target of intervention	Other targets of intervention	Intervention name[a]	Intervention category	Site of intervention	Delivered by	Structure
Barry (2010)	10 CYP with **Cancer**	Coping, distress	NA	Music therapy CD creation (MTCD)	Music therapy	MTCDs produced in hospital waiting space. Music played in radiation therapy treatment room.	Music therapist	1 CD/CYP, 1 session per CD. Session Duration: 10-90 minutes (CD length 20-90m)
Baruch (2010)	6 CYP with **Cancer**	Psychosocial adjustment, coping, resilience, self-esteem, mastery, self-transcendence	Social integration, confidence/ mastery, uncertainty in illness	Beads of Courage Program	Narrative/ Psychosocial support/Reward programme	Paediatric cancer centre	Clinician	Duration 2.5 months-3 years.
Bignall (2015)	15 African American CYP with **Asthma**	Anxiety	Asthma symptoms	Relaxation/ Breathing retraining	Relaxation (Breathing)	School-based health centre + home practise	Researcher	2 30-minute sessions once per month

First author, Date	Participants	Mental health target of intervention	Other targets of intervention	Intervention name[a]	Intervention category	Site of intervention	Delivered by	Structure
Bluebond-Langer (1991)	50 CYP with **Cancer**	Self-esteem, coping	Peer relationships	Camp Can-Do	Camp	YMCA camp facility	Volunteer	1-week long camp
Brodeur (2005)	26 Total sample: 10 CYP with LTC , 13 Parents (9 mothers, 4 fathers), 3 Siblings.	Mental health	Social support, family cohesion	Living Well Program	Family art therapy	Children's Museum	Program coordinator, clinical/ counselling psychology doctoral student, counsellors volunteers	14 2-hour weekly sessions. 5 month gap between first and last 7 sessions.
Brothers (2014)	22 young women with **HIV**	Emotional wellbeing, self-esteem, managing emotions (stress, anger, negative thinking)	Control, empowerment, improve relationships, role of alcohol and drugs, reduce secondary HIV transmission	Evolution: Young women taking charge and growing stronger…a secondary prevention empowerment intervention	Group intervention/ Group therapy	Clinical sites in three cities	Intervention deliverers	9 2-3 hours weekly sessions

First author, Date	Participants	Mental health target of intervention	Other targets of intervention	Intervention name[a]	Intervention category	Site of intervention	Delivered by	Structure
Bultas (2015)	50 CYP with **CHD**	Self-esteem, self-efficacy, anxiety	Peer support, attitude to LTC	Overnight summer recreational camp	Camp	NR	Camp Counsellor	1 5-day camp
Burns (2010)	7 CYP with **Cancer**	Reduce symptom distress, improve coping	Understanding of LTC, family relationships	Therapeutic Music Video	Music Therapy	NR	Music therapist	6 sessions
Campbell (2010)	6 African Adolescents with **HIV**	Emotional/ Psychological skills, coping	Behavioural skills; managing HIV related issues, HIV education, engagement with health professionals	Looking forward project	Group Work	Non clinical environment (e.g. church hall, restaurant) in London	Clinical psychologists, HIV clinical nurse specialist	3 1-day sessions per year

First author, Date	Participants	Mental health target of intervention	Other targets of intervention	Intervention name[a]	Intervention category	Site of intervention	Delivered by	Structure
Curle (2005)	11 Children with LTC 12 Parents	Coping and adaptation	Social support for children and parents	Terrific Tuesday Group (TTG)	Group therapy	Specialist unit'	Clinical psychologist, occupational therapist, mental health nurses, specialist paediatric nurses, social workers	6 to 8 weekly sessions
Dennison (2010)	16 CYP with **CFS** 16 Parents	Emotional responses	Managing physical symptoms and functional impairment	Family focused CBT vs Psycho-education	CBT, psychoeducation	Hospital	NR	NR

First author, Date	Participants	Mental health target of intervention	Other targets of intervention	Intervention name[a]	Intervention category	Site of intervention	Delivered by	Structure
Desai (2014)	13 CYP with **CHD**	Coping, self-esteem, psychosocial needs	Social support, healthcare outcomes, physical needs	Therapeutic weekend camp	Camp	South-eastern USA campsite	Trained college students and community-based volunteers. 3 registered nurses, 1 paediatric cardiologist Camping facility employees	1, 2-day camp.
Docherty (2013)	16 Adolescents with **Cancer**	Illness-related distress; improved coping	Family environment, perceived social support, derived meaning, resilience, quality of life	Therapeutic music video (TMV) intervention	Music Therapy	Hospitals: 6 paediatric and 3 adult hospitals across the United States	Music Therapist	6 1-hour sessions

First author, Date	Participants	Mental health target of intervention	Other targets of intervention	Intervention name[a]	Intervention category	Site of intervention	Delivered by	Structure
Fair (2012)	7 Adolescents with **HIV**	Mental health, problem solving, management of emotions and stress of medication side-effects	Control, physical health, adherence	Teens Out Loud creative writing groups	Creative writing (Group)	NR	Group Leaders	8 4-hour sessions per year. Once per month in fall and spring
Gan (2010)	8 Adolescents with **ABI** 14 Family members (9 parents, 1 partner, 4 siblings)	Emotional recovery, coping, anger and stress management	Education re: brain injury and effects on family, enabling independence, managing transitions, skill building, goal setting, problem-solving	Brain Injury Family Intervention for Adolescents (BIFI-A)	Family intervention/ therapy	Family home or rehabilitation centre.	2 social workers, 1 rehabilitation counsellor	7 (sometimes 8-9) 1-2 hour sessions held over 3.3 months (mean duration). range 1.5–5.0 months

First author, Date	Participants	Mental health target of intervention	Other targets of intervention	Intervention name[a]	Intervention category	Site of intervention	Delivered by	Structure
Gaysynsky (2015)	43 CYP with **HIV**	Emotional support, esteem support. coping	Engagement of services with clients	Young Adult Programme (YAP) Facebook group	Online support group	Facebook	Self, group moderated by social worker from YAP	NA
Gillard (2011)	24 CYP with **HIV**	Coping	Transition into adulthood. Living with HIV/AIDS managing AIDS related issues	Camp Strong and Teen Forum	Camp	NR	Counsellors, medical staff, psychosocial staff, and the camp director	1 6-day camp per year
Gillard (2013)	10 CYP with **Cancer**	Emotional healing and/or self-esteem	Independence, self-esteem, "normality", social inclusion recreation	Residential camp program	Camp	Camp in Southern United States	Medical staff from cancer centre, volunteers.	1 7-day camp per year
Gillard (2016)	24 CYP with LTC	Psychosocial aspects	Developmental support, building skills	The Hole in the Wall Gang Camp (THITWGC)	Camp	Medical speciality camp Connecticut	NR	1 7-day camp per year

First author, Date	Participants	Mental health target of intervention	Other targets of intervention	Intervention name[a]	Intervention category	Site of intervention	Delivered by	Structure
Griffiths (2015)	12 CYP with **Cancer**	Self-esteem, emotional support, coping	Social support, medical knowledge, acceptance of disease, sense of belonging	Realshare online community	Online support group	NA	First 3 months: self; 2nd 3 months self+ facilitator	2 3-month phases. 2nd phase 3-5 times a week.
Hosek (2012)	17 Young women with **HIV**	Mental health, psychological concerns	Coping with HIV related issues	Secondary prevention intervention for young HIV-positive women	Secondary Prevention	NA	NA	NA
Jaser (2014)	20 Adolescents with **Type 1 Diabetes**	Positive affect, stress coping	Adherence, Self-management	Check It!	Positive affirmation	NR for initial interview. Home	Parent and research assistants	1 initial interview, 16 Phone calls: 2 every week
Kashikar-Zuck (2016)	17 Adolescents with **JFM**	Coping skills	Increase exercise participation, reduce pain, confidence	FIT Teens	CBT + Neuromuscular exercise training	Children's hospital	Psychology post-doc and master's student	16 60-minute sessions, twice per week

First author, Date	Participants	Mental health target of intervention	Other targets of intervention	Intervention name[a]	Intervention category	Site of intervention	Delivered by	Structure
Kirk (2016)	97 CYP with **CF** and 182 Parents posted	Emotional support	Social support, self-care	Online Support Group	Online Support Group	Online	Self	NA
(Lewis (2016)	4 Adolescents with LTC (new members); 4 Adolescents with LTC (established members); 19 Parents of new members; 5 Co-ordinators	Self-esteem and diminish psychological distress	NA	Chronic Illness Peer Support (ChIPS)	Peer Support	Children's Hospital	Nurse (supported by a volunteer and other medical and allied health staff members).	8 2-hour weekly introductory sessions, session. 4 social events a year, one annual camp

First author, Date	Participants	Mental health target of intervention	Other targets of intervention	Intervention name[a]	Intervention category	Site of intervention	Delivered by	Structure
MacDonald (2010)	5 CYP with **Cystic Fibrosis**	Self-esteem, stress	Empowerment and independence, boredom and social isolation, self-confidence, general wellbeing	Cool Friends	Befriending programme	NR	Volunteers	Frequency of meetings ranged from once to monthly across participants. Duration of befriender relationship ranged from one month-two years across participants.
Marsac (2012)	15 CYP with **Cancer** 15 Parents	Augment coping, decrease distress	NA	Cellie Cancer Coping Kit	Coping kit (consider education or coping strategies)	Home and hospital	Self/parent	Used Cellie independently for 4 weeks

First author, Date	Participants	Mental health target of intervention	Other targets of intervention	Intervention name[a]	Intervention category	Site of intervention	Delivered by	Structure
Masuda (2013)	14 CYP with **Asthma and Life Threatening Allergies** 8 parents 5 peer mentors	Coping (self-efficacy, isolation)	Peer relationships	Professionally mediated online support intervention: Ability online	Online support	Online	Self, peer mentor, health promotion professionals	12 60-minute, weekly chat sessions
Moola (2015)	15 CYP with **CHD** and their bereaved siblings	Psychosocial stress	Quality of Life. fun, social, skill building, isolation, independence, confidence, mastery	Camp Willowood	Camp	Camp Willowood, 200km North of Toronto	Volunteers: child survivors of chronic illnesses, doctors and nurses provide medical care	NR

First author, Date	Participants	Mental health target of intervention	Other targets of intervention	Intervention name[a]	Intervention category	Site of intervention	Delivered by	Structure
Muskat (2016)	16 CYP with **HIV**	Anxiety and depression	Understanding of HIV related issues, social support	Open-ended, long term support groups	Support Group	Hospital for Sick Children Family-Centered HIV clinic	Social workers	Once monthly sessions. Median sessions attended: 12, range 3–20
Nicholas (2007)	9 CYP with LTC	Worry, anxiety, coping	Social support, engagement with treatment, knowledge, pain management	Starbright world	Online games, education and Peer support network	Online peer dialogue with patients in over 95 children's hospitals	Self	All used the network a minimum of three times
Nicholas (2009)	22 CYP with **Asthma**	Self-efficacy, coping, stress management	Social support, self-management skills, adherence barriers	Residential Summer Camp	Asthma education delivered at Summer Camp	Ontario, Canada	Paediatric health care professionals, nurse, respiratory therapist, social worker	Air force sessions: daily during 2 week long camp

First author, Date	Participants	Mental health target of intervention	Other targets of intervention	Intervention name[a]	Intervention category	Site of intervention	Delivered by	Structure
Nicholas (2012)	15 CYP with **Type 1 diabetes**	Coping, wellbeing, stress	Social support, self-management, managing relationships	Online education and support	Online education and support	Online	Self, website moderator	8 weekly modules
Nieto (2015)	15 CYP with **FAP** and their families	Stress management, catastrophizing, coping strategies	Parenting behaviours, prevention of long term disability and pain	DAR-Web	Online psychoeducation	Online	Self	7 30-minute weekly modules, completed by parents and children separately
Nilsson (2009)	21 CYP with **Cancer**	Procedural distress	Procedural pain	VR game	Game/Virtual Reality/	NR assumed hospital. Use VR during procedure	Self	Once per procedure, 6-10 minutes
O'Callaghan (2011)	26 CYP with **Cancer**	Mood, coping	Play activity, engagement,	Music therapy	Music therapy	Hospital (inpatient and outpatient settings)	Music therapist/self	NA.

First author, Date	Participants	Mental health target of intervention	Other targets of intervention	Intervention name[a]	Intervention category	Site of intervention	Delivered by	Structure
O'Callaghan (2012)	12 CYP with **Cancer**	Self-esteem and stress management	Spirituality, confidence/ mastery, hope, and self-transcendence	Music therapy	Music, music therapy	NR	Music therapist	NA
O'Callaghan (2013)	CYP with **Cancer**	Psychosocial domains, mood, well-being	Quality of life, educational, and physical domains, engagement, play, empowerment/ control	Music, including music therapy	Music therapy	3 hospitals in Melbourne, Australia	Music Therapists	NA
Reme (2013)	12 CYP with **CFS**	Decrease stress	CFS symptoms	Lightning Process	The Lightning Process	NR (various)	Lightning Process Practitioners	3 3-5 hour sessions, once per day
Romero (2014)	74 CYP with **Cystic Fibrosis**	Psychological well-being	Disease management, social support		Online education and support	Online	Self	NA

First author, Date	Participants	Mental health target of intervention	Other targets of intervention	Intervention name[a]	Intervention category	Site of intervention	Delivered by	Structure
Serlachius (2012)	13 Adolescents with **Type 1 Diabetes**	Coping/diabetes stress	Glycaemic control	Best of Coping (BOC)	Coping skills intervention	NR	NR	10 Sessions
Shrimpton (2013)	40 CYP with **Cancer**	Fear of radiotherapy/ procedural distress, anxiety	Comfort, understand radiotherapy process and communicate this to people around them	Movie making programme	Creative therapy/ Narrative therapy	Peter MacCallum Cancer Centre, Melbourne, Australia.	Radiation therapists	NR
Sibinga (2011)	5 CYP with **HIV**	Stress and psychological distress, rumination, anxiety	Improved physical health as result of decreased stress (HRQOL) enhancing non-judgmental present-focused awareness	Mindfulness-based stress reduction (MBSR)	Mindfulness-based stress reduction	Clinic assumed	MBSR instructor	9 Weekly sessions

First author, Date	Participants	Mental health target of intervention	Other targets of intervention	Intervention name[a]	Intervention category	Site of intervention	Delivered by	Structure
Stewart (2011a)	20 CYP with **Asthma** and/or **Severe Allergies**	Coping, reduce stresses	Social support, loneliness	Psychosocial Support	Games and Online peer support	Online	Facilitators: 3 female, 2 male mentors with cerebral palsy or spina bifida, 2 psychologists.	NA
Stewart (2013a;2013 b)	27 CYP with **Asthma** and/or **Severe Allergies**	Coping	Education, social support	Online support intervention	Online Support Group/Mentoring	Online	5 Peer mentors with asthma and allergies (13-20 years old), a psychologist	8 45-120 minute weekly sessions, 1-5 hours per week
Stinson (2008)	36 CYP with **Juvenile Idiopathic Arthritis**	Self-efficacy, Psychological consequences	Knowledge, self-management behaviours	Web-based program of self-management	Online support	NR	NR	NR

First author, Date	Participants	Mental health target of intervention	Other targets of intervention	Intervention name[a]	Intervention category	Site of intervention	Delivered by	Structure
Stinson (2010)	19 CYP with **Juvenile Idiopathic Arthritis** 19 Parents	Stress	Social support, symptom management, JIA-specific education,	Teens Taking Charge: Managing Arthritis Online	Online self-management /education programme	Online	Self	1 40-minute trial session
Tiemens (2007)	4 CYP with **craniofacial difference**	Self-esteem	Social support, reducing isolation, task mastery, self-reflection, therapeutic gain	AboutFace	Camp	Outdoor recreational facility	Staff at recreational facility, social workers	1 weekend
Weekes (1993)	10 CYP with **Cancer** 10 CYP with **Renal Failure**	Coping	NA	Hand-holding	Hand-holding	Outpatient hospital setting	Parent/ Clinician (nurse)	NA
White (2014;2016)	9 CYP with **CHD**	Stress reduction	Social relationships, belonging and acceptance	Camp Oki	Camp	Camp Oki Canada	Staff and volunteers at Hospital for Sick Children	1 7-day camp, once a year

First author, Date	Participants	Mental health target of intervention	Other targets of intervention	Intervention name[a]	Intervention category	Site of intervention	Delivered by	Structure
Whittemore (2010)	13 Adolescents with **Type 1 Diabetes**	Coping skills, stress management, self-efficacy	Diabetes management, self-talk, social relationships	TEENCOPE and the Managing Diabetes Internet interventions programme	Internet coping skills training program	Online, otherwise not reported.	NR	TEENCOPE: 5 sessions, Managing Diabetes: 4 weekly sessions.
Wolf Bordonaro (2005)	3 CYP with **Sickle Cell Disease**	Anxiety, stress management	Control, independence, self-responsibility	Art Therapy	Art Therapy	Patients hospital room or hospital activity room.	Art Therapist	3 1-hour art therapy sessions within 1 or 2 days
Wright (2004)	12 CYP with **Cerebral Palsy**	Self-esteem, self-efficacy	Wellbeing, self-determination, empowerment, personal and social responsibility, physical/social skills, empowerment, self-worth	Personal and Social Responsibility Model (PSRM)/Developmental Martial Arts Program (DMAP)	Physical activity	Assumed paediatric outpatient unit	Martial arts instructor/research assistant instructor physical therapists	13 45-minute weekly sessions

[a] Intervention or components named in study Key: BIFI-A = Brain Injury Family Intervention for Adolescents, CBT = Cognitive Behavioural Therapy, CFS = Chronic Fatigue Syndrome, CHD = Congenital Heart Disease, ChIPS = Chronic Illness Peer Support, DMAP = Developmental Martial Arts Program, FAP = Functional Abdominal Pain, HRQOL = Health Related Quality of Life, JFM = Juvenile Fibromyalgia, MBSR = Mindfulness Based Stress Reduction, MTCD = Music Therapy CD Creation, NA = Not Applicable, NR = Not Reported, PSRM = Personal and Social Responsibility Model, TMV = Therapeutic Music Video, TTG = Terrific Tuesday Group, VR = Virtual Reality , YAP = Young Adults Programme , YMCA = Young Men's Christian Association.

Table 61: Articles contributing to constructs and themes

Construct	Theme	Number of articles contributing to theme	Articles
Therapeutic Foundation	Safe Space	19	(Ayers et al., 2011; Barnetz & Feigin, 2012; Dennison et al., 2010; Desai et al., 2014; Fair et al., 2012; A. Gillard et al., 2011; Griffiths et al., 2015; Lewis et al., 2016; Moola et al., 2015; Muskat et al., 2016; Nicholas et al., 2007; O'Callaghan et al., 2013; Serlachius et al., 2012; Stewart et al., 2013b; Tiemens et al., 2007; Weekes et al., 1993; L. White, 2014; Whittemore et al., 2010; Wolf Bordonaro, 2005)
	Boundaries	34	(Barnfather et al., 2011; Bluebond-Langer et al., 1991; Brodeur, 2005; Brothers et al., 2014; Campbell et al., 2010; Curle et al., 2005; Dennison et al., 2010; Desai et al., 2014; Docherty et al., 2013; Fair et al., 2012; Gan et al., 2010; Gaysynsky et al., 2015; A. Gillard & Allsop, 2016; Ann Gillard & Watts, 2013; A. Gillard et al., 2011; Griffiths et al., 2015; Hosek et al., 2012; Kirk & Milnes, 2016; MacDonald & Greggans, 2010; Masuda et al., 2013),(Moola et al., 2015; Muskat et al., 2016; Nicholas et al., 2007; Nicholas et al., 2012; Nicholas et al., 2009; Romero, 2014; Sibinga et al., 2011; Stewart, Barnfather, et al., 2011; Stewart et al., 2013b; Stewart, Masuda, et al., 2011) (Tiemens et al., 2007),(L. White, 2014; Whittemore et al., 2010; Wright et al., 2004)
	Unconstrained	28	(Barnetz & Feigin, 2012; Barnfather et al., 2011; Bluebond-Langer et al., 1991; Brodeur, 2005; Bultas et al., 2015; Campbell et al., 2010; Dennison et al., 2010; Desai et al., 2014; Docherty et al., 2013; Fair et al., 2012; A. Gillard & Allsop, 2016; Ann Gillard & Watts, 2013; A. Gillard et al., 2011; Kirk & Milnes, 2016; Lewis et al., 2016; MacDonald & Greggans, 2010; Moola et al., 2015; Muskat et al., 2016; Nicholas et al., 2007; Nicholas et al., 2009; O'Callaghan et al., 2011; O'Callaghan et al., 2012; O'Callaghan et al., 2013; Stewart et al., 2013b; Tiemens et al., 2007; L. White, 2014; L. C. White et al., 2016; Wright et al., 2004)
	Therapeutic Relationships	42	(Ayers et al., 2011; Barnetz & Feigin, 2012; Barnfather et al., 2011; Baruch, 2010; Bignall et al., 2015),(Bluebond-Langer et al., 1991; Brodeur, 2005; Brothers et al., 2014),(Dennison et al., 2010; Desai et al., 2014; Docherty et al., 2013; Fair et al., 2012; Gan et al., 2010; Gaysynsky et al., 2015; A. Gillard & Allsop, 2016; Ann Gillard & Watts, 2013; A. Gillard et al., 2011; Griffiths et al., 2015; Hosek et al., 2012; Kashikar-Zuck et al., 2016; Kirk & Milnes, 2016; Lewis et al., 2016; MacDonald & Greggans, 2010; Moola et al., 2015; Muskat et al., 2016; Nicholas et al., 2007; Nicholas et al., 2012; Nicholas et al., 2009; O'Callaghan et al., 2011; O'Callaghan et al., 2012; O'Callaghan et al., 2013; Reme et al., 2013; Romero, 2014; Serlachius et al., 2012; Shrimpton et al., 2013; Stewart, Barnfather, et al., 2011; Stewart et al., 2013b; Stewart, Masuda, et al., 2011; Tiemens et al., 2007; L. White, 2014; Whittemore et al., 2010; Wolf Bordonaro, 2005)
Social Support	I am not alone	46	(Barlow et al., 1999; Barnetz & Feigin, 2012; Barnfather et al., 2011; Baruch, 2010; Bluebond-Langer et al., 1991; Brodeur, 2005; Brothers et al., 2014; Bultas et al., 2015; Campbell et al., 2010; Curle et al., 2005; Dennison et al., 2010; Desai et al., 2014; Docherty et al., 2013; Fair et al., 2012; Gan et al., 2010; Gaysynsky et al., 2015; A. Gillard & Allsop, 2016; Ann Gillard & Watts, 2013; A. Gillard et al., 2011; Griffiths et al., 2015; Hosek et al., 2012; Kashikar-Zuck et al., 2016; Kirk & Milnes, 2016; Lewis et al., 2016; MacDonald & Greggans, 2010; Marsac et al., 2012; Masuda et al., 2013; Moola et al., 2015; Muskat et al., 2016; Nicholas et al., 2007; Nicholas et al., 2012; Nicholas et al., 2009; Nieto et al., 2015; O'Callaghan et al., 2012; Reme et al., 2013; Serlachius et al., 2012; Stewart, Barnfather, et al., 2011; Stewart et al., 2013a, 2013b; Stewart, Masuda, et al., 2011; J. N. Stinson et al., 2008; Tiemens et al., 2007; L. White, 2014; L. C. White et al., 2016; Whittemore et al., 2010; Wright et al., 2004)

Construct	Theme	Number of articles contributing to theme	Articles
	Emotional and Informational Support	40	(Barnetz & Feigin, 2012; Barnfather et al., 2011; Barry et al., 2010; Baruch, 2010) (Bignall et al., 2015; Bluebond-Langer et al., 1991) (Brodeur, 2005; Brothers et al., 2014; Campbell et al., 2010; Dennison et al., 2010; Desai et al., 2014; Fair et al., 2012; Gan et al., 2010; Gaysynsky et al., 2015; Ann Gillard & Watts, 2013; A. Gillard et al., 2011; Griffiths et al., 2015; Hosek et al., 2012; Kashikar-Zuck et al., 2016; Kirk & Milnes, 2016; MacDonald & Greggans, 2010; Masuda et al., 2013; Moola et al., 2015; Muskat et al., 2016; Nicholas et al., 2007; Nicholas et al., 2012; Nicholas et al., 2009; Nieto et al., 2015; O'Callaghan et al., 2012; O'Callaghan et al., 2013; Romero, 2014; Serlachius et al., 2012; Stewart, Barnfather, et al., 2011; Stewart et al., 2013a, 2013b; Stewart, Masuda, et al., 2011) (J. Stinson et al., 2010; J. N. Stinson et al., 2008; Weekes et al., 1993; Wolf Bordonaro, 2005)
	Improved Relationships	34	(Barlow et al., 1999; Barnetz & Feigin, 2012; Barry et al., 2010; Baruch, 2010; Bignall et al., 2015; Bluebond-Langer et al., 1991; Brodeur, 2005; Burns et al., 2010; Curle et al., 2005; Desai et al., 2014; Docherty et al., 2013; Fair et al., 2012; Gan et al., 2010; Gaysynsky et al., 2015; Ann Gillard & Watts, 2013; A. Gillard et al., 2011; Hosek et al., 2012; Jaser et al., 2014; Lewis et al., 2016; MacDonald & Greggans, 2010), (Marsac et al., 2012; Nicholas et al., 2007; O'Callaghan et al., 2011; O'Callaghan et al., 2012; O'Callaghan et al., 2013) (Serlachius et al., 2012; Shrimpton et al., 2013; Sibinga et al., 2011; Stewart, Barnfather, et al., 2011; Stewart et al., 2013a, 2013b; J. N. Stinson et al., 2008; Wolf Bordonaro, 2005; Wright et al., 2004)
A Hopeful Alternative	Hope and Inspiration	30	(Barlow et al., 1999; Barnetz & Feigin, 2012; Barnfather et al., 2011; Baruch, 2010; Bluebond-Langer et al., 1991; Brodeur, 2005; Bultas et al., 2015; Burns et al., 2010; Campbell et al., 2010; Dennison et al., 2010; Fair et al., 2012; A. Gillard & Allsop, 2016; Ann Gillard & Watts, 2013; A. Gillard et al., 2011; Hosek et al., 2012; Kashikar-Zuck et al., 2016; Kirk & Milnes, 2016; Lewis et al., 2016; Moola et al., 2015; Nicholas et al., 2009; O'Callaghan et al., 2012; Stewart, Barnfather, et al., 2011; Stewart et al., 2013a, 2013b; J. Stinson et al., 2010; J. N. Stinson et al., 2008; Weekes et al., 1993; L. White, 2014; Wolf Bordonaro, 2005; Wright et al., 2004)
	I’m More than Just My Illness	33	(Barlow et al., 1999; Barnetz & Feigin, 2012; Barnfather et al., 2011; Brothers et al., 2014; Burns et al., 2010; Campbell et al., 2010; Dennison et al., 2010; Desai et al., 2014; Fair et al., 2012; Gan et al., 2010; A. Gillard & Allsop, 2016; Ann Gillard & Watts, 2013; A. Gillard et al., 2011; Griffiths et al., 2015; Hosek et al., 2012; Kashikar-Zuck et al., 2016; Kirk & Milnes, 2016; Moola et al., 2015; Muskat et al., 2016; Nicholas et al., 2007; Nicholas et al., 2012; O'Callaghan et al., 2012; O'Callaghan et al., 2013; Reme et al., 2013; Romero, 2014; Serlachius et al., 2012; Shrimpton et al., 2013; Stewart, Barnfather, et al., 2011; Stewart et al.; J. N. Stinson et al., 2008; L. White, 2014; Whittemore et al., 2010; Wolf Bordonaro, 2005)
	A New Normal	39	(Barlow et al., 1999; Barnetz & Feigin, 2012; Baruch, 2010; Bluebond-Langer et al., 1991; Brodeur, 2005; Bultas et al., 2015; Burns et al., 2010; Campbell et al., 2010; Dennison et al., 2010; Desai et al., 2014; Docherty et al., 2013; Fair et al., 2012; A. Gillard & Allsop, 2016; Ann Gillard & Watts, 2013; A. Gillard et al., 2011; Griffiths et al., 2015; Hosek et al., 2012; Kashikar-Zuck et al., 2016; Kirk & Milnes, 2016; Lewis et al., 2016; Marsac et al., 2012; Moola et al., 2015; Muskat et al., 2016; Nicholas et al., 2007; Nicholas et al., 2012; Nicholas et al.; O'Callaghan et al., 2011; O'Callaghan et al., 2012; O'Callaghan et al., 2013; Reme et al., 2013; Shrimpton et al., 2013; Sibinga et al., 2011; Stewart, Barnfather, et al., 2011; Stewart et al., 2013a, 2013b; J. N. Stinson et al., 2008; L. White, 2014; Wolf Bordonaro, 2005; Wright et al., 2004)
	Mutuality	33	(Barlow et al., 1999; Barnetz & Feigin, 2012; Barnfather et al., 2011; Bignall et al., 2015; Bluebond-Langer et al., 1991; Brodeur, 2005; Burns et al., 2010; Desai et al., 2014; Ann Gillard & Watts, 2013; A. Gillard et al., 2011; Griffiths et al., 2015; Hosek et al., 2012; Kashikar-Zuck et al., 2016; Kirk & Milnes, 2016; Lewis et al., 2016; MacDonald & Greggans, 2010; Marsac et al., 2012; Masuda et al., 2013; Muskat et al., 2016; Nicholas et al., 2007; Nieto et al., 2015; O'Callaghan et al., 2011; Serlachius et al., 2012; Shrimpton et al., 2013; Stewart, Barnfather, et al., 2011; Stewart et al., 2013b; J. Stinson et al., 2010; J. N. Stinson et al., 2008; Tiemens et al., 2007; Whittemore et al., 2010; Wright et al., 2004)

Construct	Theme	Number of articles contributing to theme	Articles
Resilience	Managing Myself	49	(Barlow et al., 1999; Barnetz & Feigin, 2012; Barry et al., 2010; Baruch, 2010; Bignall et al., 2015; Bluebond-Langer et al., 1991; Brodeur, 2005; Brothers et al., 2014; Burns et al., 2010; Campbell et al., 2010),(Curle et al., 2005; Dennison et al., 2010; Desai et al., 2014; Docherty et al., 2013; Fair et al., 2012; Gan et al., 2010; Ann Gillard & Watts, 2013; A. Gillard et al., 2011; Hosek et al., 2012; Jaser et al., 2014; Kashikar-Zuck et al., 2016; Kirk & Milnes, 2016; Lewis et al., 2016; MacDonald & Greggans, 2010),(Marsac et al., 2012; Moola et al., 2015; Muskat et al., 2016; Nicholas et al., 2007; Nicholas et al., 2012; Nicholas et al., 2009; Nieto et al., 2015; Nilsson et al., 2009; O'Callaghan et al., 2011; O'Callaghan et al., 2012; O'Callaghan et al., 2013; Reme et al., 2013; Serlachius et al., 2012; Shrimpton et al., 2013; Sibinga et al., 2011; Stewart, Barnfather, et al., 2011; Stewart et al., 2013a, 2013b; Stewart, Masuda, et al., 2011) (J. Stinson et al., 2010; J. N. Stinson et al., 2008; Weekes et al., 1993; L. White, 2014; Whittemore et al., 2010; Wolf Bordonaro, 2005)
	Empowerment	47	(Ayers et al., 2011; Barlow et al., 1999), (Barry et al., 2010; Bignall et al., 2015; Bluebond-Langer et al., 1991; Brodeur, 2005; Brothers et al., 2014; Bultas et al., 2015; Burns et al., 2010; Campbell et al., 2010; Dennison et al., 2010; Desai et al., 2014; Docherty et al., 2013; Fair et al., 2012; Gan et al., 2010; A. Gillard & Allsop, 2016; Ann Gillard & Watts, 2013; A. Gillard et al., 2011; Hosek et al., 2012; Jaser et al., 2014),(Kashikar-Zuck et al., 2016; Kirk & Milnes, 2016; Lewis et al., 2016; MacDonald & Greggans, 2010; Masuda et al., 2013; Moola et al., 2015; Muskat et al., 2016; Nicholas et al., 2007; Nicholas et al., 2009):(O'Callaghan et al., 2011; O'Callaghan et al., 2012; O'Callaghan et al., 2013; Reme et al., 2013; Serlachius et al., 2012; Shrimpton et al., 2013; Sibinga et al., 2011; Stewart, Barnfather, et al., 2011; Stewart et al., 2013a, 2013b; J. Stinson et al., 2010; J. N. Stinson et al., 2008; Tiemens et al., 2007; Weekes et al., 1993; L. White, 2014; L. C. White et al., 2016; Wolf Bordonaro, 2005; Wright et al., 2004)
	Self-Esteem	27	(Barnetz & Feigin, 2012; Barry et al., 2010; Baruch, 2010; Brodeur, 2005; Brothers et al., 2014; Burns et al., 2010; Campbell et al., 2010; Dennison et al., 2010; Desai et al., 2014; Gan et al., 2010; Gaysynsky et al., 2015; A. Gillard & Allsop, 2016; Ann Gillard & Watts, 2013; A. Gillard et al., 2011) (Hosek et al., 2012; Jaser et al., 2014; Kashikar-Zuck et al., 2016; Kirk & Milnes, 2016; Nicholas et al., 2007; Shrimpton et al., 2013; Stewart, Barnfather, et al., 2011; Stewart et al., 2013a, 2013b; Tiemens et al., 2007; L. White, 2014; Whittemore et al., 2010; Wright et al., 2004)
Getting In and Staying In	Availability	30	(Barlow et al., 1999; Barnetz & Feigin, 2012; Barnfather et al., 2011; Campbell et al., 2010; Dennison et al., 2010; Desai et al., 2014; Docherty et al., 2013; Fair et al., 2012; Gan et al., 2010; Ann Gillard & Watts, 2013; A. Gillard et al., 2011; Griffiths et al., 2015; Hosek et al., 2012; Kashikar-Zuck et al., 2016; Lewis et al., 2016; MacDonald & Greggans, 2010; Masuda et al., 2013; Muskat et al., 2016; Nicholas et al., 2007; Nicholas et al., 2009; O'Callaghan et al., 2011; O'Callaghan et al., 2012; Reme et al., 2013; Stewart et al., 2013b; J. N. Stinson et al., 2008; Weekes et al., 1993; L. White, 2014; L. C. White et al., 2016; Whittemore et al., 2010; Wolf Bordonaro, 2005)
	Accessibility	52	(Barlow et al., 1999; Barnetz & Feigin, 2012; Barnfather et al., 2011; Barry et al., 2010; Baruch, 2010; Bignall et al., 2015; Brodeur, 2005; Brothers et al., 2014; Bultas et al., 2015; Burns et al., 2010; Campbell et al., 2010; Dennison et al., 2010; Desai et al., 2014; Docherty et al., 2013; Fair et al., 2012; Gan et al., 2010; Gaysynsky et al., 2015; A. Gillard & Allsop, 2016; Ann Gillard & Watts, 2013; A. Gillard et al., 2011) (Griffiths et al., 2015; Hosek et al., 2012; Jaser et al., 2014; Kashikar-Zuck et al., 2016; Kirk & Milnes, 2016; Lewis et al., 2016; MacDonald & Greggans, 2010; Marsac et al., 2012; Masuda et al., 2013; Moola et al., 2015; Muskat et al., 2016; Nicholas et al., 2007; Nicholas et al., 2012; Nicholas et al., 2009; O'Callaghan et al., 2011; O'Callaghan et al., 2012; O'Callaghan et al., 2013; Reme et al., 2013; Romero, 2014; Serlachius et al., 2012; Shrimpton et al., 2013; Stewart, Barnfather, et al., 2011; Stewart et al., 2013b; Stewart, Masuda, et al., 2011; J. Stinson et al.; J. N. Stinson et al., 2008; Tiemens et al., 2007; L. White, 2014; L. C. White et al., 2016; Whittemore et al., 2010; Wolf Bordonaro, 2005; Wright et al., 2004)

Construct	Theme	Number of articles contributing to theme	Articles
	Engagement	54	(Barlow et al., 1999; Barnetz & Feigin, 2012; Barnfather et al., 2011; Barry et al., 2010; Baruch, 2010; Bignall et al., 2015; Bluebond-Langer et al., 1991; Brodeur, 2005; Brothers et al., 2014; Bultas et al., 2015; Burns et al., 2010; Campbell et al., 2010; Curle et al., 2005; Dennison et al., 2010; Desai et al., 2014; Fair et al., 2012; Gan et al., 2010; Gaysynsky et al., 2015; A. Gillard & Allsop, 2016; Ann Gillard & Watts, 2013; A. Gillard et al., 2011; Griffiths et al., 2015; Hosek et al., 2012; Jaser et al., 2014; Kashikar-Zuck et al., 2016; Kirk & Milnes, 2016; Lewis et al., 2016; MacDonald & Greggans, 2010; Marsac et al., 2012; Masuda et al., 2013; Moola et al., 2015; Nicholas et al., 2007; Nicholas et al., 2012; Nicholas et al., 2009; Nilsson et al., 2009; O'Callaghan et al., 2011; O'Callaghan et al., 2012; O'Callaghan et al., 2013; Reme et al., 2013; Romero, 2014; Shrimpton et al., 2013; Sibinga et al., 2011; Stewart, Barnfather, et al., 2011; Stewart et al., 2013a, 2013b; Stewart, Masuda, et al., 2011; J. Stinson et al., 2010; J. N. Stinson et al., 2008; Tiemens et al., 2007; Weekes et al., 1993; L. White, 2014; Whittemore et al., 2010; Wolf Bordonaro, 2005; Wright et al., 2004)
	Keeping it going	42	(Ayers et al., 2011; Barlow et al., 1999), (Barnetz & Feigin, 2012; Barry et al., 2010), (Baruch, 2010; Bignall et al., 2015; Bluebond-Langer et al., 1991; Brodeur, 2005; Brothers et al., 2014; Bultas et al., 2015; Desai et al., 2014; Fair et al., 2012; Gan et al., 2010; A. Gillard & Allsop, 2016; Ann Gillard & Watts, 2013; A. Gillard et al., 2011; Griffiths et al., 2015), (Jaser et al., 2014; Kashikar-Zuck et al., 2016; Kirk & Milnes, 2016; Lewis et al., 2016; MacDonald & Greggans, 2010; Marsac et al., 2012; Moola et al., 2015; Nicholas et al., 2007; Nicholas et al., 2009; Nieto et al., 2015; O'Callaghan et al., 2011; O'Callaghan et al., 2012; O'Callaghan et al., 2013; Reme et al., 2013; Shrimpton et al., 2013; Sibinga et al., 2011; Stewart, Barnfather, et al., 2011; Stewart et al., 2013a, 2013b; J. N. Stinson et al., 2008; Tiemens et al., 2007; L. White, 2014; L. C. White et al., 2016; Whittemore et al., 2010; Wolf Bordonaro, 2005)

Table 72: First, second and third-order construct data contributing towards theme development in Review 2

Theme: Safe Space				
Idea for further interpretation/ Third Order Construct	Second Order Construct	Quote	Contributing Papers	Acknowledgement of overlap with other constructs
Familiarization with intervention	Participants had few pre-conceptions about what therapy would involve,...(Dennison et al., 2010) The nightly format of Teen Talk was predictable; ground rules were discussed, information was shared, and campers received candy afterwards. (Desai et al., 2014) Some agree to music therapy only after observing other children's sessions. They maybe "vicariously" engaged even though apparently disinterested. (O'Callaghan et al., 2013) By the end of each subjects' first art therapy session, the parameters of art therapy as a "safe place" and the role of the art therapist as the person in the hospital who addressed psychosocial needs was internalized by each of the subjects. (Wolf-Bordonaro, 2003) In order to calm the nerves of their children, caregivers tried to familiarize their children with the camp experience. This entailed meeting with a camp coordinator, introducing their children to other children with CHD prior to camp, or familiarizing their children with the camp environment and staff through viewings on Facebook and/or YouTube.(White, 2014)	Parents also mentioned the benefits of play therapy in managing needle-related distress…."Children practice injecting into an orange. It took a couple of sessions, but that's how we got round it in the end" (P9:Mother). (Ayres et al., 2011) "This was because of his previous experience with drums, this is because of that internal feeling memory he has at home. When he plays the drums at home he feels good and when he's playing the drums now he's re-experiencing that feeling." (O'Callaghan et al., 2013)	Ayres et al., 2011, Dennison et al., 2010, Desai et al., 2014, O'Callaghan et al., 2013, White, 2014, Wolf-Bordonaro, 2003	Getting In and Staying In: Engagement, Boundaries

Theme: Safe Space			
Presence of a familiar person	Children and parents said how important it was that parents support their child during needle-procedures. They provided children with familiarity, reassurance, security, and practical support. (Ayres et al., 2011) Familiarity with their cardiologists may provide the initial confidence necessary for children and their parents to make the decision to attend camp. (Desai et al., 2014) Group leaders cited a strong connection with social workers and other community resources as fundamental to the success of a creative writing group for adolescents living with HIV. (Fair et al., 2012) Participating in an open-ended long-term group and having the same health care team involved in their care provided many of the older teens with a predictable, secure support system.(Muskat et al., 2016) Adolescents preferred to have their hand held by a family member such as a parent, a sibling, an aunt, an uncle, or some other relative. When neither parents nor other relatives were available, nurses were next în preference. (Weekes et al., 1993)	"If I actually knew the nurse it would be okay, but if I didn't I would be like 'what's going on? I don't even know you!" (C12:B:12) (Ayres et al., 2011) "Right at the beginning when I hadn't met anybody and didn't know where I was going and all those kinds of things, ummm, being quite young, being very ill, very worried. And I personally wouldn't have coped very well if they had just invited me to go to somewhere. I needed my mum there" (Dennison et al., 2010) "[H]aving [their social worker] in the room made a big difference because, as I mentioned, she came in for lunch the first two sessions. And then the third session she stayed in the classroom the whole time and it was much more. . .it made a big difference in the kids participating vocally." (Fair et al., 2012)	Ayres et al., 2011, Dennison et al., 2010, Desai et al., 2014, Fair et al., 2012, Muskat et al., 2016, Weekes et al., 1993

Theme: Safe Space			
Familiar setting	One participant in the focus group for new ChIPS members spoke of hospital as a good place to meet because it was ‘‘common ground’’, that is, somewhere familiar to all participants (New ChIPS Member Group) Lewis et al., 2016 Offering a support group at the hospital, in a location that is familiar and easily accessed was described as important by the majority of group participants and their parental caregivers.(Muskat et al., 2016)	“Perhaps participants would feel a bit more easy knowing it’s in a hospital environment. Parents may feel a little more at ease than dropping them off at some random hall in some neighbourhood. I think it’s a safer environment within the hospital.” (Co-ordinator 3)(Lewis et al., 2016)	Lewis et al., 2016, Muskat et al., 2016

		Theme: Safe Space		
Fear of not knowing anyone	While most children enjoyed online dialogue with peers, a few children described discomfort in forging relationships with unknown persons and discussing personal health details in online interaction. (Nicholas et al., 2007)	Some group members directly articulated anxiety over being accepted by new and unfamiliar group members. One group member noted, "My only worry was that I was afraid that I wouldn't really click with everyone else or some people that have different stories than mine and I'd be too afraid to say something." (Fair et al., 2012)	Dennison et al., 2010, Fair et al., 2012, Nicholas et al., 2007	Engagement: Overlaps with worries re: not knowing anyone

Theme: Safe Space			
Getting to know peers/setting	Furthermore, the direct and ongoing encounter with the mentors over a year enables the mentees to learn about many things they do not dare ask about, or even problems they were previously unaware of. (Barnetz et al., 2012) this novel and daunting situation. (Dennison et al., 2010) Awareness of commonalities and lack of isolation fostered feelings of camp as a home. (Gillard et al., 2011) Beyond meeting others, adolescent participants highly valued the opportunity to socialize and become acquainted with one another. (Tiemans et al., 2007) The interventions were designed to increase the internality of subjects' LOC by familiarizing them with the hospital environment, (Wolf-Bordonaro, 2003)		Barnetz et al., 2012, Dennison et al., 2010, Gillard et al., 2011, Tiemans et al., 2007, Wolf-Bordonaro, 2003
Reminders of home/Link to somewhere safe	Family style meal times and clean up were reported as meaningful by nine campers. (Desai et al., 2014) Therapists' singing of live familiar songs for patients in procedures like lumbar punctures, scans, venepunctures, and central line changes have also prevented the need for sedation. The session is like a "bubble" where protection is offered, containing, holding, and easing a child's distress. Music offers a familiar means of engaging with something comprehendible, with a beginning and end. Soothing familiar sounds can provide structure amid the chaos and uncertainty of serious, harsh treatments, and boring hospital routines. (O'Callaghan)	"I think this place is like a home away from home for all of us, like, a haven." (Gillard et al., 2013) "I was diagnosed and started treatment at the beginning of high school so for me, the hospital became like a second home. It was my safe haven. I always felt safe in the hospital. I always felt comforted in the hospital. So having the 8-week group in the hospital, I saw it as somewhere safe that I could come back to, … Even now, when I'm part of the adult system, I love coming back here cos it's still like my bubble." (Lewis et al, 2016) We are a pretty close group so I always	Desai et al., 2014, Gillard et al., 2013, Lewis et al., 2016, O'Callaghan et al., 2013, Muskat et al., 2016

Theme: Safe Space				
		see these guys here. So it’s like, it’s probably easier here cause it’s like, how do you say it, here it’s like a happy home so it’s like, as an example like, let’s say, if we are all like a family and our grandma lived here, and grandma invited us all over for dinner every three months, that’s how it is, like whenever we come it’s like ‘Hey, good to see you.’ (Muskat et al., 2016)		
Familiarity with peers facilitating access to social support	These supports also offered interaction, support, commitment, and relationships that may be experiences as comfortable and nurturing as a family (Muskat et al., 2016) Analysis of participant and parental caregiver interviews revealed that nearly all group participants described the support they experienced in the group and a sense of safety, acceptance, and comfort as a result of their participation in the program (Muskat et al., 2016)	“The camp did help with that [to talk about our different experiences] by bringing us all together and letting us get to know each other for a couple of days so that we felt that we were comfortable enough to go up to each other and just talk about it (CFDs).” (Tiemans et al., 2007)	Muskat et al., 2016, Tiemans et al., 2007	Social support

		Theme: Safe Space		
Facilitator establishing connection	Under-appreciated in the literature is campers' relationship with counsellors who participate along with them in activities, encourage them to push their limits, and facilitate interactions among camp peers. Our research adds to the literature by supporting an earlier study which documented that supportive staff–camper interaction is an important process at camp which allows campers to establish meaningful relationships (Desai et al., 2014), Although campers formed friendship networks outside of camp, it was possible that some of the campers on the fringes of social groups might have lacked access to these networks. To ensure equitable access to social networks after camp, camp administrators could provide formal and informal opportunities for further relationship building and nurturing for campers. ..In addition, the more they participated in camp, the less likely they were to see HIV as stigmatizing, or something of which to be ashamed...Further opportunities for forming caring connections could include increased time to share concerns and information, ways for campers to discover similarities with other campers, and engaging in fun recreation activities that make these other goals palpable to youth (Gillard et al., 2011) Camp administrators are urged to strategically plan for opportunities for campers to share concerns and issues about cancer by training counselors to facilitate the discussions. (Gillard et al., 2013) The group leaders facilitated the development of a mutual aid system, in which members described helping themselves while and through helping one	"[H]aving [their social worker] in the room made a big difference because, as I mentioned, she came in for lunch the first two sessions. And then the third session she stayed in the classroom the whole time and it was much more. . .it made a big difference in the kids participating vocally." (Fair et al., 2012) "I think it's my contact throughout the year that really keeps them linked in with the program and I'm the constant in ChIPS. So I'm the one that's at everything. I'm always there. I'm always the one that emails them. I'm always the one that hounds them for permission notes and invites them to things, so I think they connect with me first, and then through me, connect with others." (Co-ordinator 4) (Lewis et al., 2016) A health care provider stated, "I'm fortunate enough to have an enclosed area where I have generally more than one teen on (the network) at a time. So I end up introducing them to each other." (Nicholas et al., 2007) "I remember on the first day, a number of people were shy, including me, so [mentor] would start the conversation and then give people ideas and then that happened to me too, so I can tell that story so then that got the ball rolling. There really needed to be someone to ask the questions and	Desai et al., 2014, Fair et al., 2012, Gillard et al., 2011/13, Griffiths, Lewis et al., 2016, Muskat et al., 2016, Nicholas et al., 2007, Serlachius et al., 2012, Stewart et al., 2013a, Tiemans et al., 2007, Whittemore et al. 2010,	Engagement: opportunity to get to know one another

Theme: Safe Space				
	another. (Muskat et al., 2016) Mediating and/or facilitating this encounter among teen peers, social workers can play an important role in engaging conversation, initiating group work, finding common topical ground or points of interest and ultimately in allowing teens privacy for peer dialogue (Nicholas et al., 2007) These findings emphasize the important role that health care professionals play in fostering trust and encouraging individuals to take a more active role in managing their illness (Serlachius et al., 2012) In the online support intervention, mentors encouraged children to talk about their feelings and support needs. (Stewart et al., 2013a) In addition to increased leader-facilitated discussion about facial difference, adolescents wanted open discussions without a leader present. (Tiemans et al., 2007) The TEENCOPE Internet program included a health professional (a clinical psychologist) as the moderator who contributed to the conversations in the discussion board to stimulate discussion, provide feedback, and provide suggestions for problem solving. (Whittemore et al. 2010)	move it along and make it so that everyone had a turn, say what they really thought and helping everybody." (11-year-old girl with allergies) (Stewart et al., 2013a) "It is good to have a leader but maybe not [one] who does everything . . . like especially when we didn't know each other at first it was really tough to get us to talk. ...So it might be good to have a leader at first but once we got to know each other it was a little easier." (Tiemans et al., 2007)		
Boundaries	The nightly format of Teen Talk was predictable; ground rules were discussed, information was shared, and campers received candy afterwards. (Gillard et al., 2011)		Gillard et al., 2011	Boundaries facilitating safe space

Theme: Safe Space				
Control and feeling safe	Each subject solicited information regarding the exact time and place where the following session would take place, and then asked the art therapist to repeat this information when she returned to her room. This knowledge was particularly meaningful to the subjects, and provided an important measure of control. Wolf-Bordonaro, 2003		Wolf-Bordonaro, 2003	
Time to develop connections	Temporal relations also featured centrally in CHD youths' camp experiences. The participants' main complaint about Camp Willowood is that its one-week duration is 'too short', compromising the formation of long-lasting friendships. (Moola et al., 2015) A camper suggested a longer camp time frame "because it would give us more time to hang out and make friends." (Tiemans et al., 2007)		Moola et al., 2015, Tiemans et al., 2007	Engagement. Also Therapeutic Relationships (Development of trust): Time needed to overcome anxiety and access therapeutic relationships

Theme: Boundaries				
Idea for further interpretation/ Third Order Construct	Second Order Construct	Quote	Papers contributing	Acknowledgement of overlap with other constructs
Fear of being exposed (in society and intervention setting)	Most participants mentioned that it was helpful being part of a group in which difficult explanations about status were not required and where there was no secrecy: (Campbell et al., 2010) Concerns related to disclosure of their HIV status are seen in the following excerpts from Positive Voices Speak Out (2009):...There's always the risk of confidentiality being breached.(Fair et al., 2012) According to a Teen Talk facilitator, the most effective locations for group dynamics and learning were those where individuals in the group could hang back and observe if they wished. It was important for campers to be able to hide their emotions within the larger group if they needed to, because "[i]t be real deep at Teen Talk" (Gillard, 11) At home I'm like Clark Kent . . . but like here, I'm Superman. I'm just like, I'm more open, more talkative, more inspired. . . . 'Cause when I'm at my home it's like I'm hiding from everybody else. And that's sad because I don't want to, but it's like I'm in the phone booth and it seem [sic] like I can't even be around you, so, I just don't communicate. Camp is more open, it's just friends all over. (Gillard et al., 2011) Freed from society's stigmatizing labels	Even when participants did not identify specific concerns, they noted that other members were worried about possible disclosure. For example, one adolescent said, "I wasn't worried. [but] other people were worried about their names getting out."" You can come up with a nickname, or it can be anonymous. You can be absolutely anonymous in this group." (Fair et al., 2012) "It's not so easy, especially when sometimes the (others) . . . want to talk about their illness ...,and (the local ill child) doesn't at all." (Nicholas et al., 2007)	Campbell et al., 2010, Fair et al., 2012, Gillard et al., 2011/16, Nicholas et al., 2007, Sibinga et al., 2011, Stewart et al., 2013a	

Theme: Boundaries			
	associated with their illnesses, they could be themselves and pursue their own interests and desires. It is this freedom to be themselves that helped shape the camp experience for many of these camper study participants. (Gillard et al., 2016) mentioned as an important concern upon probing this issue. The MBSR methods seem to have a positive effect in terms of ameliorating HIV-specific stressors such as taking medicines, fearing illness and death, experiencing stigma and discrimination, and disclosing HIV status. (Sibinga et al., 2011) Children discussed how managing asthma and severe allergies was stressful with peers. They were worried about disclosing their condition and about reactions of other people to being breathless, use of prescribed medications, and missing sports or school because of illness. The children with food allergies were apprehensive about how their peers might treat them. (Stewart et al., 2013a)		
Privacy/Anonymity to protect	Further work may need to be developed within the family clinic to identify and support families who may be struggling. However, this would have to be balanced with families' right to privacy and respect for their wishes if they do not want their young person to participate (Campbell et al., 2010) Despite this, many young people, and a few	"I did wonder whether they should have spoken to her by herself. Because one of the things that happens with a sick child is they spend a lot of time at home. And there are a lot of other things going on and I just felt like there could be things going on that are	Campbell et al., 2010, Dennison et al., 2010, Docherty et al., 2013, Gillard et al., 2011, Gaysynsky, Hosek et al.,

Theme: Boundaries			
	parents, felt that there were certain situations where the young person should have been seen alone and some issues that would be better discussed separately.(Dennison et al., 2010) Younger campers were in bed by Teen Talk time, and older campers were less concerned about having the younger ones overhear them discuss HIV/AIDS and about needing to ensure the care of the younger ones...(Gillard, 11) The individual sessions would allow women to ‘‘get things off their chest’’ and provide in-depth discussions with a counselor or therapist (Hosek et al., 2012) Anonymity did not appear to be a concern for most participants. Although most participants used a pseudonym as a user name, they frequently used actual names in their postings (Kirk et al., 2016) Accurate information about HIV, its transmission, its impact on social relations and use of medication is very important for these children and teens. These issues are not commonly discussed by parental caregivers and their children. Therefore, providing a safe and accessible venue to discuss this information is both needed and beneficial. (Muskat et al., 2016)	of worry and whether friends like you etcetera that may not want to be said in front of parents.” (Dennison et al., 2010)	2012, Kirk et al., 2016, Muskat et al., 2016

Theme: Boundaries		
Role of interventionist in creating private/safe space (from parents/interventionist) or preserving anonymity	Findings regarding ambivalence towards family involvement may prompt clinicians to reconsider the extent of family involvement in therapy, perhaps opting for some sessions alone with the young patient, (Dennison et al., 2010) Most had longstanding relationships with the social worker who first introduced the idea of a creative writing group. Their trust in her contributed to their confidence that the group experience would be helpful. (Fair et al., 2012) Formal online moderation only appeared to occur when personal information was shared. (Kirk et al., 2016)	Dennison et al., 2010, Fair et al., 2012, Kirk et al., 2016,
Respective privacy/autonomy	The third core theme in the parent benefit category, TMV intervention as a valued way for parents to respect and support AYA privacy and independence...centers on how parents understood and valued their AYA's need for privacy, autonomy, and opportunities to exercise independence and the ways in which the TMV intervention helped them honor and support these fundamental needs....Subthemes included honoring and valuing AYA privacy needs related to DVD creation and respect for AYA decisions regarding who would view the DVD. (Docherty et al., 2013)	Docherty et al., 2013

Theme: Boundaries			
Challenge to health profs	Moreover, with increased availability of online therapies, professional colleges are still determining the legal and ethical mandates of working with clients online to ensure protection of personal health information (Gan et al., 2010) Parents highlighted the need for visual examples, sequencing, and the opportunity to practice. They also expressed concerns about security and privacy...In addition, the moderator of TEENCOPE played an important role in evaluating the safety and psychosocial integrity of participants....Internet sites for this study were password protected, with all data encrypted and stored on a secure server with hardware and software firewalls to protect information within the server. (Whittemore et al. 2010)		Gan et al., 2010, Masuda et al., 2013, Whittemore et al. 2010,
Opportunity to spend time together as family or peers	They did not need to take time away from what they viewed as the major reasons for going to camp: 'the activities,' "having a good line,' and "being with other children with cancer." (Bluebond-Langer et al., 1991) The adolescents with ABI and their family members noted that they enjoyed being in the sessions together and having the opportunity to share and interact with each other openly. They commented that this opportunity had not presented itself before and they appreciated the honest dialogue that occurred (Gan et al., 2010) The importance of camp friendships for	“Do you know what about the program that allowed you guys to get closer together? R: Probably just doing things, just some of the activities for the kids. It basically gave us an opportunity to go with the family to one place. We’re usually scattered all over the place, going here, there, o r.. .so. So, I just think that was just a chance for everybody to kinda get together. Participant #16 - Father - It gave us a chance to spend more	Bluebond-Langer et al., 1991, Brodeur, 2005, Gan et al., 2010, Gillard et al., 2011

Theme: Boundaries			
	youth with chronic illness has been well documented (Bluebond-Langer et al., 1991Langner et al., 1991). In Bluebond-Langer et al., 1991-Langner et al.’s study, camp relationships for youth with cancer were characterized by qualities of empathy, understanding, and acceptance, and were unlike their relationships with healthy peers. (Gillard et al., 2011)	time together. And to cooperate more.” - (Brodeur, 2005) “Helped us to discuss concerns and feelings that otherwise might not surface” [mother 6]. “Each of us had a turn to speak and share “ [sibling 1].” Opened my eyes as to what [the adolescent with the ABI] was thinking” [father 4] (Gan et al., 2010)	

Theme: Boundaries			
Boundaries/Anonymity to help facilitate expression of emotion/containment	The lunch also offered a break from what could be an emotional experience, (Campbell et al., 2010) The third core theme in the parent benefit category, TMV intervention as a valued way for parents to respect and support AYA privacy and independence...centers on how parents understood and valued their AYA's need for privacy, autonomy, and opportunities to exercise independence and the ways in which the TMV intervention helped them honor and support these fundamental needs....Subthemes included honoring and valuing AYA privacy needs related to DVD creation and respect for AYA decisions regarding who would view the DVD. (Docherty et al., 2013) A major camp process that facilitated campers building awareness of commonalities was Teen Talk, a 1- to 2-hour education-based workshop held during four of the five nights of camp. Teen Talk was another adult-facilitated forum in which campers aged 12 to 16 connected because they were able to discuss matters related to HIV/ AIDS only in this setting.(Gillard, 11) Perceived anonymity among computer users encouraged open communication, information exchange, and coping. (Nicholas et al., 2007) A few parents believed that their children contributed to the group more comfortably, because they were not in the same room with their peers...They contended that the	A parent highlighted a perceived level of anonymity associated with online support by stating, "being on the computer sometimes (allows you to) talk more than you can when you sit down face to face ...(There is) ...anonymity about it." Despite knowing that others would read online comments, a sense of privacy appeared to yield heightened self-expression. (Nicholas et al., 2007) "The Internet was better because you're not looking at them straight in the eye. I guess it is a bit easier. I think I shared my feelings better. Face-to-face would be hard." (Stewart et al., 2013a)	Campbell et al., 2010, Docherty et al., 2013, Gillard et al., 2011, Nicholas et al., 2007, Stewart et al., 2013a,

	Theme: Boundaries	
	anonymity of the Internet helped private and shy children to participate.(Stewart et al., 2013a)	

Theme: Boundaries			
Respecting personal space and boundaries of others (role of interventionist/other)	Still, counselors placed boundaries on transgressions, such as drawing limits at invading individuals' personal spaces. (Gillard et al., 2013) Although she did not see changes in social skills, Ms. Munday stated that the group dynamic included elements that Gary needed: The “dynamic in-group helps Gary to understand the social rules like taking turns and respecting limits.” (Wright et al., 2004)	“I think that maybe some rules and expectations should have been laid down at the beginning, as to what was expected from each family, i.e. kids, parents, that kind of thing. R: What were some of the things like rules or expectations that you didn’t feel were said too directly? P: You mean, what should have been said? R: Yeah. P: Like um, like at the beginning when you had your group activity with your family, sometimes, they would want us to sit in other places than where we were, and that was okay, just let us know that at the beginning. The kids, you know, I think it’s extremely important when you are dealing with children, regardless of illness or age, that they know from the get go, what is expected, and what their limitations are. And it wasn’t really explained to them that you can’t run around the museum, or that you can run around the museum at this time, um, like this is a quiet place and you need to walk and use a quiet voice. The kids went in not really knowing what the limitations were.Yeah, and then when they are imposed after the fact, it feels	Brodeur, 2005, Gillard, 2013; Wright et al., 2004,

Theme: Boundaries			
		restrictive... P: Well, it’s kind of like when you try to put rules after the fact, it’s just not effective. You know, you gotta do that from the get go. Like a classroom, you have got to set your expectations from the beginning.” Participant #15 - M other - Post-Interview (Brodeur, 2005)	
Respecting boundaries: non explicitly discussed	…in relation to socially acceptable discussion topics and interactional style. There was no evidence of impoliteness or ‘flaming’ and postings expressing feelings of anger were seen as acceptable as long as they were not directed...Although the groups were a place where negative emotions could be expressed, it appeared that there were boundaries to this. Indeed, the online group was not always seen as being an appropriate place to discuss certain experiences and	“That it’s got a sense of community. that everybody respects everybody; . and you can talk about everything and anything.. Some people disagree with you, but they don’t bark at you” (Stewart et al., 2011)	Stewart et al., 2011, Kirk et al., 2016

<table>
<tr><th colspan="3">Theme: Boundaries</th></tr>
<tr><td></td><td>feelings...The life-limiting nature of CF was not ...explicitly discussed apart from one parent asking for information about the process of death....Other research has similarly discovered that online group norms are established that determine acceptable discussion topics8 (Kirk et al., 2016)</td><td></td></tr>
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Theme: Boundaries			
Behavioural boundaries:	Another 11-year-old camper who recognized counsellors’ role in setting boundaries and monitoring camper activity levels expressed his sense of security (Desai et al., 2014) Finally, the facilitators modeled behavior expectations throughout their presentations of the material. (Gillard et al., 2011)	“And then you know that when she goes there, there’s enough staff and there’s enough people around that they won’t let that [bullying] happen and it makes such a great environment that that’s [bullying] not even an issue. “(Julie) (White, 2014)	Desai et al., 2014, Gillard et al., 2011, White, 2014

Theme: Boundaries				
Flexible boundaries/Boundaries not always needed	Members of planning committees also have wondered about the value and feasibility of offering formal group discussions at camp about cancer and the effects of realmet. This does not seem warranted, however, because the children were able to find opportunities to exchange information, thoughts, feelings, and attitudes in the context of every-day camp activities (Bluebond-Langer et al., 1991-Langner et al., 1990) (Bluebond-Langer et al., 1991) Secondly, researchers should consider the implications of avoiding a 'taboo' topic (Bluebond-Langer et al., 1991 1978) that is clearly of great existential import to cardiac youth at a camp for youth with chronic illnesses – the (Moola et al., 2015) In terms of camp programming for this population, findings suggest that psychosocial issues can be addressed both through spontaneous interactions as well as structured and facilitated group dialogues addressing specific issues for teens. (Tiemans et al., 2007)		Bluebond-Langer et al., 1991, Moola et al., 2015, Tiemans et al., 2007	Contrasts with: Acceptance of Death(A new normal)

Theme: Unconstrained				
Idea for further interpretation	Second Order Construct	Quote	Papers Contributing	Acknowledgement of overlap with other constructs
Freedom to be themselves/from stigma	As Greenwood and Dax (1982) mentioned, the children in their study felt more comfortable about their appearance and abilities and did not fear ridicule from their peers. (Bluebond-Langer et al., 1991) Participants remarked that it was helpful to be with other HIV' young people. Most participants mentioned that it was helpful being part of a group in which difficult explanations about status were not required and where there was no secrecy (Campbell et al., 2010) Being open and not having secrets provided hope and fun (Campbell et al., 2010) Feeling like everyone else/not feeling judged (Desai et al., 2014) …and positive affect, especially given the absence of stigma. (Gillard et al., 2011) She and others noted that at camp, people did not react negatively to scars or other visible effects of cancer. (Gillard et al., 2013) Many camper study participants talked about the ability to be themselves while at camp because no one was judging them.(Gillard et al., 2016) Youth with CHD reflected on how they are perceived as fragile in their everyday lives by parents, teachers and friends at schools. Further, youth commented on how they are often held back and restricted from engaging in active pursuits at home. In contrast,	“The other patients know what you're going through, and the other friends they're not sure what you're going through and sometimes they go "ooh,' "yuck," and stuff like that.” (10-year-old female) (Bluebond-Langer et al., 1991) One 12-year-old camper reflected while explaining why he returned to camp each year: “You make new friends every year and you get to understand your heart defects with them. I just like hanging out with friends and being able to relate to people cause at my school there is nobody else with heart problems so when I run . . . in the gymI can’t really relate, nobody can relate to me,they are like ‘are you slowing down?’ But at camp, when I am tired they are like ‘oh I understand’, so it helps a lot.” (Desai et al., 2014) “I think what makes camp special is a lot of people, it's second nature to judge and when you just come here, everybody is in a judge-free zone and you can just be weird and have fun and	Bluebond-Langer et al., 1991, Campbell et al., 2010, Desai et al., 2014, Gillard et al., 2011/13/16, Moola et al., 2015, Muskat et al., 2016	Link to Hope and Inspiration and Social support

Theme: Unconstrained			
	Camp Willowood provides them with the opportunity to move their bodies without limit. The process by which camp enhanced perceptions of bodily freedom was related to greater independence, opportunities to be more physically active (Moola et al., 2015) Group interventions have been demonstrated to be effective approaches for the delivery of support and education for children and teens with medical conditions and are highly recommended, especially for conditions associated with stigma. (Muskat et al., 2016, 16)	nobody's there to judge you." (Gillard et al., 2016) "At home I'm like Clark Kent . . . but like here, I'm Superman. I'm just like, I'm more open, more talkative, more inspired. . . . 'Cause when I'm at my home it's like I'm hiding from everybody else. And that's sad because I don't want to, but it's like I'm in the phone booth and it seem like I can't even be around you, so, I just don't communicate. Camp is more open, it's just friends all over." (Gillard et al., 2011)	

Theme: Unconstrained				
Freedom from stigma/to be self in mixed groups.	Feeling like everyone else/not feeling judged (Desai et al., 2014) These two campers identified lack of judgment as being a defining characteristic of what camp means to them. The ability to be themselves without fear of ridicule or being ashamed of their serious illness was a powerful influence on many camper study participants. Similarly, one camper replied, (Gillard et al., 2016) Benefits of peer interaction were multi-faceted. Participants described outcomes of feeling understood, developing new friendships, expressing their own ideas, and increasing personal mastery and a sense of independence...Children enjoyed connecting with peers with a similar condition; an opportunity that, for some, was largely unavailable (Nicholas et al., 2007)	"I think one good thing about Living Well... Well, there's a lot of good things about Living Well, but I think of what I find helps me with Living Well is just being around people that have the same problems. Not necessarily the same illness, but just dealing with the same things in a different disease. Like for instance, the second meeting we were in our therapy groups and the counseling groups asked, "What are some of the things you do at home to cope?" But I noticed that (other participant's) mother said that she cleans. And she hates talking on the phone. And I do the same thing. I hate talking on the phone. I just don't want to deal with the phone. And that made me feel normal. If you gave somebody else the same problem, they would be doing the same thing I'm doing, so I'm normal. So, that's something that I got out of Living Well this time that helps. It makes you realize you are normal, even though you feel like you're going Crazy."(Brodeur, 2005)	Brodeur, 2005, Desai et al., 2014, Gillard et al., 2016, Nicholas et al., 2007	Link to a new perspective/connection with similar peers (I am not alone)

Theme: Unconstrained				
Escape/Freedom: Link to normalcy	The experience provided multiple activities that many of the children would not have an opportunity to experience because of their heart condition; this included zip-lining, float trips, archery, swimming, and fishing. (Bultas et al., 2015) Participants recognized opportunities to enjoy freedom, spend time and play outdoors, and appreciate the natural surroundings, while learning and having fun. (Desai et al., 2014) Our results showed that even within the time span of a weekend, participants experienced freedom and peacefulness in the camp's natural surroundings. (Desai et al., 2014) Campers experienced freedom from responsibilities and the need to hide at home, and freedom to engage in fun and challenging recreation activities. (Gillard et al., 2011) Campers saw camp as a place to enjoy themselves, to participate in activities that they normally would be unable to do at home because of lack of availability or accessibility (especially for those with mobility impairments). (Gillard11) Youth engaged in physical activities they could not do at home due to cancer treatments and real or perceived limitations based on illness placed on youth by their caregivers. Engaging in new and fun activities connected to feelings of freedom. (Gillard et al., 2013) To describe their embodied camp experiences to us, CHD youth contrasted and compared these feelings to their bodily experiences in	"Mainly just for (ill child) to get to know others kids and it gives her something to look forward to - to come down here - because they have a good time because a lot of time she is shut up in the house some so you know, every chance that we get to get her out and have fun - that's my main goal." (Parent - Brodeur, 2005) "at camp we just have a lot of freedom, we are in the middle of nowhere . . . you can't really wreck anything, you have more room to do more activities. Because we are in the woods there is . . . just a lot of open areas where you can run.' Another 11-year-old male expressed, 'We have more freedom. And there is a lot more things to do than just sit around and watch TV, play video games and do school work. You get to play around and be yourself.' The natural environment and the open spaces seemed to encourage participants to engage in free play and exploration." (Desai et al., 2014) "I get to do all these fun activities, like archery, horseback riding, the zip line [an activity in which the participant rides or "zips" down a long, taut cable suspended	Brodur, Bultas et al., 2015, Desai et al., 2014, Gillard et al., 2011/13, Moola et al., 2015, Nicholas et al., 2007, White, 2014/16	Link to Adaption under Accessibility. Link to Normalacy. Overlap with safe space.

Theme: Unconstrained			
	everyday, ordinary environments at home. In their everyday lives, the children’s main bodily orientation was the experience of bodily restriction. This stood in stark contrast to the enhanced physical ability of their bodies when attending camp(Moola et al., 2015). In addition, the ability to also engage in a topic of interest unrelated to illness was appreciated, especially given that the focus of hospitalization primarily revolved around their own illness and treatment. (Nicholas et al., 2007) Furthermore, parents identified that their children would be in a safe, inclusive, and non-restricting environment surrounded by health care professionals who would be familiar with their children’s health condition, be aware of the signs and symptoms of a cardiac episode, and not restrict them from participating in daily camp activities. This was thought to provide parents with a sense of ease knowing that their children would be in the best capable hands: (White et al., 2016) Lastly, these caregivers anticipated that their children would be able to experience camp just like their typically developing peers (White, 2014)	between two tall poles], the rock climbing thing. Um, it’s something I don’t always get to do.” (Gillard et al., 2011) “They're more free than in the hospital. (Interviewer: What are they free to do here?) They're free to run around, they're free to get outside and have some fresh air, they're free from the IV pole, free to have fun.” (Gillard et al., 2013) “ was always like super nervous because my family has always been so cautious of what I do, that I always, I got that now too. I’m anxious of things I don’t know. Camp kinda made me realize that ‘I can – I’m underestimating myself in some situations, that I can do more than I thought I could and I really push myself more. It is just the fact that I could do like extreme et al., 2013 things at camp, without having to worry about anything. I was the first one to do the rock climbing out of my group and I’ve never done it before. And, the water skiing – I’ve never done and it’s just all these things I wouldn’t imagine doing with my health because I’d be too scared. I had nothing to worry about at camp, so it was really fun.” (Moola et al., 2015)	

Theme: Unconstrained			
		"It's going to be a growing experience for our family—to be able to let go and be able to allow him to be the child that in our hearts we know that he could be … Oh it will be a wonderful feeling knowing that he has accomplished things that we never thought he would be able to accomplish either. So it would be a great feeling for our family that, 'hey you know what, now we know that this is something he enjoys, we should get him involved in it or look where else we can do it'."(White et al., 2016) "it'll allow her to actually go to camp and experience canoeing and all the things that every healthy kids gets to experience all the time – in a controlled environment too." (White, 2014)	

Theme: Unconstrained				
Safe space to talk and share experiences	…the interviews indicated that diabetic adolescents have to cope with numerous fears and worries which in many cases, according to the mentees, cannot be shared with anybody. They cannot be shared with parents because they are overly anxious and concerned, and the mentees are afraid of adding to their worries. They cannot be shared with the medical practitioners since on numerous occasions they are experienced as judgmental and inattentive toward the adolescents, to the point where they feel they cannot speak their mind for fear of being rebuked and reprimanded. They cannot be shared with friends because they are ashamed and fear that they will be unable to understand. Consequently, the adolescents carry with them burdensome and troubling worries and fears that have an isolating effect, parts of their worldview and feelings that they cannot share with anyone. Numerous mentees reported on a change in this situation. They felt they could usually tell the truth to their mentors without fear of hurt or reprimand. (Barnetz et al., 2012) The interaction with a group of HIV-positive peers provided them with a safe place to talk openly about their experiences (Fair et al., 2012) At home, campers' expressions of grieving were typically stymied by the stigma associated with HIV/AIDS. At camp, youth discussed the deaths of family members and camp friends. (Gillard et al., 2011) Given a shared history – that they discovered	Adolescents unanimously reported increased confidence levels that were evident within the confines of the group, as well as in their everyday interactions. For example, one 15-year old male explained, "I got to speak my mind and didn't have to hold anything in."(Fair et al., 2012) "My family, not really, and outside like friends no, cause you don't really know who to trust. And even in my family it's awkward to talk about but here I know I can talk about it with these people and that's really good. I like feeling that I can talk to someone, it's really good, yeah … Here you feel like it's not taboo, you know " (Muskat et al., 2016) "Well, I like pretty much everything I like. I like the way how it's set up. I like a lot of it! I like pretty much everything! Like I liked how we had a big conversation about everything and then we answered questions and everything and looked at stuff that was actually fun and then we. . . after went to Club Penguin. I really liked it. "(8-year-old boy with asthma and allergies) (Stewart et al., 2013a) "It might be nice if next time we	Barnetz et al., 2012, Fair et al., 2012, Gillard et al., 2011, Moola et al., 2015, Muskat et al., 2016, Stewart et al., 2013a,Tiemans et al., 2007	Social support, particularly I am not alone

Theme: Unconstrained			
	on their own by asking questions, listening, hearing stories and taking perspective – the children developed a sense of affinity. (Moola et al., 2015) Analysis of participant and parental caregiver interviews revealed that nearly all group participants described the support they experienced in the group and a sense of safety, acceptance, and comfort as a result of their participation in the program.... Members discussed issues they had in common that they were not comfortable discussing with anyone else in their lives, known as “taboo topics” in the group work literature (Shulman, 2002). (Muskat et al., 2016) Almost all parents said that their children enjoyed the freedom to share their concerns with other children in similar situations, (Stewart et al., 2013a) All participants sought opportunities for adolescents with CFDs to openly discuss issues pertaining to living with a facial difference, using both spontaneous discussion and planned topical focus. (Timeans)	could all have an open discussion about our facial differences. ...If we all kind of sat in the room and talked about different experiences or something that would . . . be helpful” (Tiemans et al., 2007)	

Theme: Unconstrained			
Important for stigmatised diagnosis/visible difference	In contrast to the isolation felt at home, while at camp, youth felt that they were with others who were the same as them. There was no need to hide because everyone knew each other’s most closely held secret, and campers could easily share information and support about living with HIV/AIDS. (Gillard et al., 2011) First, stigma likely played a role in the interview responses about “being myself” for youth with sickle cell disease and HIV/AIDS. That is, outside of camp, youth with HIV/AIDS often feel constrained from telling others about their illnesses due to stigma about the conditions (Gillard et al., 2016)	“….kind of became peer counselors in a way and were able to help them answer some responses to people [.] there was one girl, the oldest girl in the class, just felt like everyone should be out and open about it and perhaps that would release the stigma. So really a means for them to figure things out on their own and figure out how they wanted to represent themselves and HIV or if they wanted that to be a part of who they were.” (Fair et al., 2012)	Fair et al., 2012, Gillard et al., 2011/16

Theme: Unconstrained				
Respite from suffering/uncertainty/ LTC/Daily life	While the TMV intervention provided a diversion, parents also felt it offered opportunity for the AYAs to exert control over the environment by making choices, creating something meaningful, and experiencing a sense of normalcy in the midst of an overwhelming focus on the illness and medical treatments (Burns et al., 2010) experiencing the therapeutic elements of the physical environment at camp. (Desai et al., 2014) included perspectives about intervention effectiveness in providing respite from daily suffering (Docherty et al., 2013) Campers were free of other worries while at camp, which was another major reason that camp was a reprieve and opportunity for recreation. In camp, leadership positions were not available to campers (although a few counselor-in-training positions existed for former campers), and campers were not responsible for any camp operations or tasks (with the exception of one cabin-based volunteer task over the course of the week). (Gillard et al., 2011) Throughout camp, several campers were observed being advised by counselors and other campers to relax, just have fun, and to be a kid. The developmental experiences related to "just being a kid" were discussed by interview and focus group participants as experiences that were not typically available to youth with cancer (Gillard13) All of these campers were dealing with serious	"It's like something you can go to where you don't have to worry about. (Brodeur, 2005) He looked forward to the [scheduled session]. He knew it was going to be a day where he didn't have to worry about if they were coming in to give him a pill or if they're coming in to start the chemotherapy." (Father, son, 16 years old) (Burns et al., 2010) A 16-year-old camper summarized, "What camp means to me is being away from all of my problems and to be with people that have been through the same thing that I have," (Desai et al., 2014) "What I think makes camp special is kind of like the isolation from like the outside of the world, like the rest of the world because – it's just like a different atmosphere." Another camper stated, "The meaning of camp in my life is – it's an escape from the real world and it's just a way to get rid of your problems and your stress and everything like that." (Gillard et al., 2016) Another health care staff member discussed that "I think it's a protected environment for them and lets them close the world to	Brodeur, 2005, Burns et al., 2010, Desai et al., 2014, Docherty et al., 2013, Gillard et al., 2011/13/16, Lewis et al., 2016, Moola et al., 2015, Nicholas et al., 2007, O'Callaghan et al., 2013, White, 2014	Safe space and Fun

Theme: Unconstrained			
	medical conditions and many of them enjoyed the ability to get away from “being sick” for a few days....Camp offered these youth the opportunity to get away from the stress of medical treatments, school assignments, doctors' visits, and the constant reminder that they are different from everyone else because they are sick. Those worries were not present at camp. (Gillard et al., 2016) This strongly supports other literature, which suggests that camp is a therapeutic landscape (Goodwin and Staples 2005, Dunkley 2009). The healing properties of nature have been recognised for centuries, dating back to the ancient Greeks who extolled the benefits of exposure to fresh air and sunlight to cure the ill (Gesler 2003). Informed by cultural ecology, humanism and structuralism, Gesler (2003) extended this idea, proposing the notion of therapeutic landscapes in 1992. These are landscapes that have restorative properties and are linked to treating various ailments. Associated with beauty, tranquilly and remoteness, therapeutic landscapes are based on the assumption that a degree of isolation from the stress associated with everyday life may be therapeutic. (Moola et al., 2015) In contrast, our results suggest that illness is an ‘ever present thought at the back of my mind’ for these children in multiple contexts, regardless of whether they are at home or at camp. (Moola et al., 2015) Participants suggested that the online network tempered the arduous and painful experiences	all the badness that's going on around them. Especially if kids are near the end.” (Gillard et al., 2013) “I did the program, the 8-week program, I was actually in hospital and so it was really good to have a break and just come down and be with people who were around about my age. “(Girl 1, ChIPS Reference Group). (Lewis et al., 2016) “in the outdoors, like you aren’t in a busy city where there’s only buildings, its just trees and the lake … and with nature – with harmony and nature’.” Sophia notes that ‘at camp, it’s quieter, which I enjoy, definitely peaceful, fresh smelling which we definitely, need because we live in the city’. Thus, the natural spatial environment was important to youths’ pleasurable camp experiences.” (Moola et al., 2015) “(the online network) has . . . helped to make the time pass a little quickly.” (Nicholas et al., 2007) Another child stated, “I probably would have found (hospitalization) a lot longer because I wouldn’t have that option to do during the day.”	

	Theme: Unconstrained		
	of hospitalization...Accordingly, children associated difficulty and sadness with hospitalization; however, online participation was seen to ease and distract participants from daily stresses (Nicholas, 07) Beyond health issues, compelling non-illness topics also were presented on the network. These increased the scope of familiar topics for conversation with family and friends; a benefit appreciated by participants. Nicholas et al., 2007 Given that cancer can dramatically alter the child’s sense of being, music can arguably be a safe haven (O’Callaghan et al., 2013) The majority of caregivers perceived that Camp Oki would allow their children to get a break from their families and realize what they can accomplish without their family or friends present (White, 2014)	(Nicholas et al., 2007) “I think that she’ll make a lot of really nice friends and I think that she’s really looking forward to that. And just being away from home and being away from us and being with different people. I think everybody just needs a break from their family every once in a while. So I think that it’s nice that she has the opportunity to take a break from us and still feel safe because she knows that this camp is for kids that have heart defects or heart disease … It’ll give her more independence, absolutely. So she’ll be able to – I’m hoping that she’ll come home and be able to pick out her own clothes … But it will give her that boost of being able to do more things independently.”(White, 2014)	

Theme: Unconstrained				
Freedom from adult rules (learning and discussion/expression)		“I liked that you could just go and get a drink. It would have been like a school trip otherwise. They got to know us, not like teachers.” (Philip, 14) (Campbell et al., 2010) A focus group participant explained that camp was “An opportunity to get away from home and do stuff that you usually aren't allowed to do at home.” (Gillard et al., 2013) “It is good to have a leader (adult interventionist) but maybe not [one] who does everything . . . like especially when we didn’t know each other at first it was really tough to get us to talk...So it might be good to have a leader at first but once we got to know each other it was a little easier.” (Tiemans et al., 2007)	Barnetz et al., 2012, Bluebond-Langer et al., 1991, Campbell et al., 2010, Dennison et al., 2010, Gillard et al., 2011, Gillard et al., 2013, Kirk et al., 2016, Moola et al., 2015, Nicholas et al., 2007, Tiemans et al., 2007, White, 2014	
Fun				See Engagement Theme
Learning something distressing through peer	The children were concerned about how to treat other patients; they feared offending	“it worries me sometimes, because they campers who	Bluebond-Langer et al., 1991,	

Theme: Unconstrained			
interaction	them and reported feeling bad, even unconformable, in the presence of children who were doing less well. (Bluebond-Langer et al., 1991) While most children enjoyed online dialogue with peers, a few children described discomfort in forging relationships with unknown persons and discussing personal health details in online interaction. Although uncommon, instances of discomfort were described, as were instances of self-consciousness over seeing oneself (or being seen by others) on camera in the context of videoconferencing. In such cases, illness-related visible changes in appearance could exacerbate embarrassment. ..A health care provider described an instance in which a participant learned upsetting information relating to another child's condition. The health care provider noted the difficulty this information presented for the recipient (Nicholas et al., 2007) Notably, there were four caregivers who expressed negative aspects relating to developing bonds amongst children with CHD. For example, Henry was concerned about his son's ability to become more aware of the severity of his own illness and exaggerate symptoms: (White, 2014)	relapsed thought that someday they'd be sure, and they could go on with their lives, And it didn't turn out that way. So once in a while, think, "Well, maybe I will relapse, and I won't be around very long." It makes me wonder whether i should just give up chemotherapy altogether and just live my life the best can for a couple of months or whatever-just go out and have a good time 'cause you don't really know what the future holds." (Bluebond-Langer et al., 1991) "So I think that there could potentially be a negative of it [interacting with other children with CHD]. If he says 'ok wait a second, I've got a heart disease, these other kids here have a heart disease and perhaps they're not as well off'. Does he say 'jeez I've got more of an issue that maybe I didn't even recognize at all?' Or does it say to him, 'jeez I'm not as normal as maybe what I was thinking I am'." (White, 2014)	Nicholas et al., 2007, White, 2014

Theme: Unconstrained				
Need for Adult/Parent free space	There were mixed feelings regarding parental involvement in therapy; although supportive and facilitative it could also be awkward and restrictive (Dennison et al., 2010)Despite this, many young people, and a few parents, felt that there were certain situations where the young person should have been seen alone and some issues that would be better discussed separately. (Dennison et al., 2010) There was evidence of cross-posting, of young people and adults with CF posting messages to the parent group and parents posting messages in the young people group. (Kirk et al., 2016) The children even started their own ‘adult free’ child-operated Facebook page, the purpose of which is to dialogue about camp, stay connected, recall camp memories and dream about future camp experiences. the children demonstrated resistance against ‘adultist’ social orders (Mayall 1998) by generating their own ‘adult-free’ Facebook page...For example, although the use of online technologies forged a temporal bridge for youth to stay connected through time, it may also be considered as an ‘online space’ for children that adults cannot occupy....(Moola et al., 2015) In addition to increased leader-facilitated discussion about facial difference, adolescents wanted open discussions without a leader present. (Tiemans et al., 2007)	“…liked that we did a kind of bring together activity first, and then I liked the fact that the parents went off without the children. R: Because it gave them time to be alone? P: Uh huh.. .and for them to meet other kids that are like them. They loved (other participant) and (other participant). Participant # 1 5 - M other - Post-Interview , pg. 2 - 3 (Brodeur, 2005) “I did wonder whether they should have spoken to her by herself. Because one of the things that happens with a sick child is they spend a lot of time at home. And there are a lot of other things going on and I just felt like there could be things going on that are of worry and whether friends like you etcetera that may not want to be said in front of parents” (P 1 2CBT). (Dennison et al., 2010) “It is good to have a leader but maybe not [one] who does everything . . . like especially when we didn’t know each other at first it was really tough to get us to talk. ...So it might be good to have a leader at first but once we got to know each other it was a little easier.” (Tiemans et al., 2007)	Brodeur, 2005, Dennison et al., 2010, Kirk et al., 2016, Moola et al., 2015, Tiemans et al., 2007	Boundaries

Theme: Unconstrained			
Appreciate talking openly when don't normally have opportunity	At home, campers' expressions of grieving were typically stymied by the stigma associated with HIV/AIDS. At camp, youth discussed the deaths of family members and camp friends.(Gillard et al., 2011) …stigma likely played a role in the interview responses about "being myself" for youth with sickle cell disease and HIV/AIDS. That is, outside of camp, youth with HIV/AIDS often feel constrained from telling others about their illnesses due to stigma about the conditions (Gillard et al., 2016) An older teen further described the importance of having a place to be with others and talk about their experiences with HIV (Muskat et al., 2016)	My family, not really, and outside like friends no, cause you don't really know who to trust. And even in my family it's awkward to talk about but here I know I can talk about it with these people and that's really good. I like feeling that I can talk to someone, it's really good, yeah … Here you feel like it's not taboo, you know? (Muskat et al., 2016)	Gillard et al., 2011/16, Muskat et al., 2016
Need for facilitator	This camper recommended blending professional leadership and peer support to maximize psychosocial goals. Beyond adolescent recommendations, parents also advocated for an increased compliment of professional facilitation and peer-based support. All participants sought opportunities for adolescents with CFDs to openly discuss issues pertaining to living with a facial difference, using both spontaneous discussion and planned topical focus. (Tiemans et al., 2007) Because of their shyness, Brandon and Jerry required more nudging than the others to take on teaching roles at first. However, they both became more comfortable and confident in this role as time progressed. (Wright et al., 2004)	"It is good to have a leader but maybe not [one] who does everything . . . like especially when we didn't know each other at first it was really tough to get us to talk. ...So it might be good to have a leader at first but once we got to know each other it was a little easier." (Tiemans et al., 2007)	Tiemans et al., 2007, Wright et al., 2004

Theme: Unconstrained				
Acknowledgement of Physical need	Another child talked about how she could not attend a ‘‘normal’’ camp because of her medical needs and felt ‘‘safe’’ and protected participating in this camp. (Bultas et al., 2015) Additionally, the medical and psychosocial teams who addressed specific individuals’ needs and were a constant presence throughout camp supported campers. (Gillard et al., 2011) The philosophy of camp was that it was not only accessible; but also “barrier-free.” Medical staff members were well aware of the health needs of individual campers, and ensured that appropriate staff and equipment were available to facilitate their participation in camp. (Gillard et al., 2013) Co-ordinators and young people spoke of the sense of physical and emotional safety that resulted from the presence of trained health care professionals in the familiar paediatric hospital setting. (Lewis et al., 2016) Since Camp Oki is operated by the Hospital for Sick Children, caregivers felt comfortable and confident leaving their child for a week. Caregivers perceived that their children would be surrounded by doctors, nurses, and staff who would be familiar with their child’s medications, be aware of the signs and symptoms of a cardiac episode, and not restrict them from participating in daily camp activities. (White, 2014) Furthermore, parents identified that their children would be in a safe, inclusive, and non-restricting environment surrounded by health care	He continued that his mother allowed him to go to this camp “‘cause they took care of you with doctors and it is a camp about heart conditions so I can relate to kids that have the same problem I do.’” (Desai et al., 2014)	Bultas et al., 2015, Desai et al., 2014, Gillard et al., 2011/13, Lewis et al., 2016, White, 2014/16	Accessibility: Acknowledgement of physical need

Theme: Unconstrained		
	professionals who would be familiar with their children’s health condition, be aware of the signs and symptoms of a cardiac episode, and not restrict them from participating in daily camp activities. This was thought to provide parents with a sense of ease knowing that their children would be in the best capable hands:(White et al., 2016)	
Theme: Therapeutic Relationships		

Theme: Therapeutic Relationships				
Idea for further interpretation/ Third Order Construct	Second Order Construct	Quote	Papers contributing	Acknowledgement of overlap
Availability/ approachability of helpful non-judgemental others	They cannot be shared with the medical practitioners since on numerous occasions they are experienced as judgmental and inattentive toward the adolescents, to the point where they feel they cannot speak their mind for fear of being rebuked and reprimanded....When facing medical practitioners the adolescents often feel guilt; they do not do all that is required of them, they are not sufficiently responsible, and therefore expect rebuke and preaching in advance. In a situation such as this it is only natural that communication on their part will not be open (Barnetz et al., 2012) If individuals felt uncomfortable asking a question in the large group setting of Teen Talk, they would take the facilitators aside during the day to ask their questions...Additionally, the medical and psychosocial teams who addressed specific individuals' needs and were a constant presence throughout camp supported campers...Increased unstructured and informal interactions allow for higher levels of attention and support at camp than in school settings or after-school programs because of higher staff–camper ratios, a greater amount of time available during a week at residential camp, and intimacy found within close living quarters such as cabins. (Gillard et al., 2011)	"that is what camp means to me, I love the counsellors. They are awesome and if you need help just ask them a question and they will help you." (Desai et al., 2014) "So then they exercise physiologist and psychologist would right away be like ok here." (Kashikar-Zuck et al., 2016) "If you ever need someone to talk to, let us know or send me an email. I am here most days and will try my best to help you." (Kirk et al., 2016) One co-ordinator spoke of the ''vulnerability and strength'' model she used as a theoretical underpinning to the Introductory Program. "[ChIPS] works on a connection model, it works on a model where support is available or demonstrated and it works on a trust relationship where vulnerabilities can be discussed and where coping with or adapting to the life that you lead as an adolescent with an illness is able to be validated,	Barnetz et al., 2012, Desai et al., 2014, Kashikar-Zuck et al., 2016, Gillard et al., 2011, Kirk et al., 2016, Lewis et al., 2016, Wolf-Bordonaro, 2003	

Theme: Therapeutic Relationships			
	Participants emphasized their availability and that of the online community to provide support for one another. These postings emphasized a sense of community using the terms ‘we’ and ‘us’. (Kirk et al., 2016) Subject 1 identified the researcher/art therapist as what seemed to be the only channel available to her in the hospital, and both verbal and visual processed psychologically demanding material... subjects’ art skills were not challenged, and closed directives were avoided. (Wolf-Bordonaro, 2003)	both through the difficulties and also through some of the resilience that you build up. So for me, ChIPS is around young people supporting young people.” (Co-ordinator 2) (Lewis et al., 2016)	
Can perceive and respond to needs	provided one-on-one support from a trained, perceptive adult, (Wolf-Bordonaro, 2003)		Wolf-Bordonaro, 2003

		Theme: Therapeutic Relationships		
Interested/validating/ Understanding/ Respecting experiences (interventionists only)	The finding that the experience of recognition, validation and being listened to was deemed critical and of importance regardless of treatment effectiveness fits well with this literature. (Dennison et al., 2010) Another leader commented, In staff–camper interactions, campers perceived counselors as having “an open heart,” wanting to hear what campers had to say, being concerned about their well-being, and being excited each summer to see campers return. Some campers mentioned how impressed they were that the counselors were all volunteers who gave up their time to work with them: “They do that for us? I appreciate it, I really do” (Gillard et al., 2011) The response to postings expressing negative emotions displayed empathy, with participants acknowledging and confirming that such feelings were justified. (Kirk et al., 2016) Music therapists endeavor to attune with children and share their journeys through therapeutic relationships, rather than impose expectations, such as those possibly anticipated by musical entertainers. (O’Callaghan, 13) The joint acceptance of a physiological rationale by the client and therapist may also mean that the client is put in a position where they may simultaneously feel that their symptoms are taken seriously and that the process is worth committing to (Reme et	“The mentor manages to come into both worlds, the world of the adults and the world of my worries, he knows them, you can choose what to share with him and what not to share, he’s tolerant. He doesn’t pressure me.” (Barnetz et al., 2012) “I wanted people to realise that there was something wrong with me::: on the outside there was nothing visibly wrong with me and I wanted recognition” (YP 7 2 PE) (Dennison et al., 2010) “And they shouldn’t be afraid to voice your opinions because like this is a very open group, very friendly, and we’ve all gone through the same thing, and we have leaders who are very understanding.” (Fair et al., 2012)	Barnetz et al., 2012, Dennison et al., 2010, Fair et al., 2012, Gillard et al., 2011, Kirk et al., 2016, O’Callaghan et al., 2013, Reme et al., 2013, Stewart et al., 2013a	Engagement

Theme: Therapeutic Relationships		
	al., 2013) The mentors also credited comparison with helping the children to realize that it was normal to have differences; skills, hopes and wishes, strengths, and weaknesses. (Stewart et al., 2013a)	

Theme: Therapeutic Relationships			
Empathy from others	Users acknowledged the difficulties of managing and living with complex drug regimens/therapies drawing on examples from their own experience... The response to postings expressing negative emotions displayed empathy, with participants acknowledging and confirming that such feelings were justified. (Kirk et al., 2016)	“It’s like talking to someone who knows how I feel.” A parental caregiver said, “She participated because I guess the communication they have in the group, they give every child a chance, an equal chance to speak, tell their story, it has helped her a great deal.” (O’Callaghan et al., 2013)	Kirk et al., 2016, O’Callaghan et al., 2013

Theme: Therapeutic Relationships				
Understood/validation (peers)	The group format-which made participants feel supported and validated in their experiences; (Kashikar-Zuck et al., 2016) An older child stated that friends who have not experienced illness “don’t understand” what life is like for a child with a rare illness. In contrast, network communication with other ill youth permitted participants to both meaningfully convey their realities, and perceive themselves to be ‘understood.’ (Nicholas et al., 2007) Parents believed that talking to peers confirmed that children’s concerns were valid, they were doing well, and they could manage difficult situations. (Stewart et al., 2013a)	"You compare notes. You get to realize that you can have the same diagnosis, you can be on the same medications, but it affects you differently." (Bluebond-Langer et al., 1991) “I think I’m doing better with some stuff. It was interesting to find out that I wasn’t the only one going through anything.. .1 think it validated some of what I was feeling and I needed validation.” (Brodeur, 2005) And they shouldn’t be afraid to voice your opinions because like this is a very open group, very friendly, and we’ve all gone through the same thing, and we have leaders who are very understanding.” (Fair et al., 2012) One co-ordinator spoke of the ‘‘vulnerability and strength’’ model she used as a theoretical underpinning to the Introductory Program. “[ChIPS] works on a connection model, it works on a model where support is available or demonstrated and it works on a trust relationship where vulnerabilities can be discussed and where coping with or adapting to the life that you	Bluebond-Langer et al., 1991, Brodeur, 2005, Fair et al., 2012, Kashikar-Zuck et al., 2016, Lewis et al., 2016, Muskat et al., 2016, Nicholas et al., 2007, Stewart et al., 2013aa, Tiemans et al., 2007, Whittemore et al. 2010	I am not alone

Theme: Therapeutic Relationships		
	lead as an adolescent with an illness is able to be validated, both through the difficulties and also through some of the resilience that you build up. So for me, ChIPS is around young people supporting young people.” (Lewis et al., 2016) “younger group reported, “It’s like talking to someone who knows how I feel.” A parental caregiver said, “She participated because I guess the communication they have in the group, they give every child a chance, an equal chance to speak, tell their story, it has helped her a great deal.” (Muskat et al., 2016) “We understand what we are going through” (Tiemans et al., 2007) “The scene presented was true…but, most of all I liked knowing that other teenagers know how I feel. That made me feel good.” (Whittemore et al. 2010)	

Theme: Therapeutic Relationships			
Feeling cared for/people being interested (peers)	Several campers overtly expressed their feelings about commemorating the anniversary of a loved one's passing while at camp, and others treated them with respect and care for their grieving. Grieving was not ignored. (Gillard et al., 2011) Campers expressed feeling a sense of love, respect, happiness, and caring throughout their time at camp. (Gillard et al., 2016) In Teen Talk, they interacted with non-judgmental campers and staff who cared about their health and well-being, and who wanted to help them overcome difficulties and achieve their goals. (Gillard et al., 2011) Youths' pleasurable experiences at Camp Willowood were explained by bodily freedom, caring relationships, (Moola et al., 2015) These supports also offered interaction, support, commitment, and relationships that may be experiences as comfortable and nurturing as a family. (Muskat et al., 2016) For some children, peer mentors were the only people other than parents who listened to them share their feelings about asthma and allergies. They assured children that mentors and other children in the group would understand and listen to them.(Stewart et al., 2013a) Second, camp was an environment that fostered caring and fun relationships among children with CHD. (White, 2014)	"Yeah, I think that before Living Well, you feel like, why bother people? Don't worry other people with your problems. But then when Living Well came along, it's like people want to be bothered like, I guess. Whether they want to learn from you or help their self, there are people out there that want to know." (Brodeur, 2005) Another leader commented, "There were kids in the first class who wouldn't talk. It wasn't like they were trying to be difficult, I mean they were just really shy. And they were the kids who were talking nonstop by the end. One girl said she was so glad that she would write about this because nobody else had ever wanted to hear about it." (Fair et al., 2012) Speaking about the theme of positive affect, one camper said, "I would take from camp the vibe that I get – the vibe of caring and respect and love that is just emanating through everything, through every activity in the cabins and everywhere....Another camper poignantly described the feelings he had as one of his key	Brodeur, 2005, Fair et al., 2012, Gillard et al., 2011/16, Moola et al., 2015, Muskat et al., 2016, Stewart et al., 2013a, White, 2014

Theme: Therapeutic Relationships
takeaways from his time at camp. He said, I would probably take that feeling of like being wanted because I know, like, for some kids when they go to high school or whatever they don't feel as, like, wanted or like people want to be around them. So I'm just, like, try to make others feel wanted and included because, like, with everything that we went through it's not, like, very often that you're included in a lot of stuff.” (Gillard et al., 2016)

		Theme: Therapeutic Relationships		
Feeling valued/cared for (interventionist)	Findings from our observations agreed with the literature that the camp structuring practices underscored participants' feelings of regard and being valued. (Gillard et al., 2011) Camp staff emphasized a camper-focused orientation, making them feel valued and cultivating an environment that opened boundaries and facilitated expression. (Gillard et al., 2013) Campers indicated that relationships between campers and staff promoted their feelings of being valued, as evidenced through statements about the staff listening, treating campers as capable, providing sympathy, and creating closeness. Campers discussed the high levels of caring they perceived from their counselors (Gillard et al., 2016) Children, parents, and mentors agreed that mentoring was a critical element in the support group. Children said that peer mentors ensured that they felt welcome, launched the meeting, and included all children. Peer mentors were role models (Stewart et al., 2013a) the reinforced knowledge that they would again soon have access to the safe place established as a parameter of art therapy sessions, and perhaps the unconditional positive regard provided by the art therapist, seemed to provide the psychological fortification they required to return to the realities of hospitalization. (Wolf-Bordonaro,	One camper commented, “What I think makes camp special is all the counselors who make you feel special. They just, like, if you feel homesick they just, um, like they'll sit with you.”...What makes camp special would be that the counselors would do anything to make the experience better for the campers. Like if you ask them to do anything, they're happy to do it. (Gillard et al., 2016) a place where they can feel safe and know that “these people are here take care of me...(Gillard et al., 2011) A Junior Counselor explained what it was about camp that made her feel valued: “And it was great for someone to always listen to me and to believe everything I said. Like if I was tired: ‘Here's a Gatorade, take a nap.’ Like it was fine, there were no worries about it, it was just everything I wanted to do. The counselors were always fun and energetic and wanted to make sure you were feeling good and wanted to make sure you were having fun. You would think that at such a	Gillard et al., 2011/13/16, Stewart et al., 2013a, Wolf-Bordonaro, 2003	Link to positive reflection of self under self-esteem? Boundaries and self-expression

Theme: Therapeutic Relationships			
	2003)	big camp, some kids would fall to the back, if they're quiet. But no, every single kid was made to feel unbelievably special in their own way.” (Gillard et al., 2013)	

Theme: Therapeutic Relationships				
Emotional release	…the ability to share experiences and not hide emotions from the mentors who understand the world from the adolescents' perspective, which for some of the mentees created an exceptionally powerful experience. (Barnetz et al., 2012) The BOC Program affords children an opportunity to visually express and elaborate their emotions. As the children are encouraged by staff to share their story, and express their feelings in a supportive environment they may also ... (Baruch, 2012) Another explanation is that for low income African-American youth, simply interacting with the research team and learning about asthma management had an immediate calming effect. (Bignall et al., 2015) For example, parents identified the lyric writing process as a means for AYA to or Gan et al., 2010ize and express their thoughts, communicate and share their experience (even private/painful aspects) with others, and bring about meaningful conversations.(Docherty et al., 2013) Helped us to discuss concerns and feelings that otherwise might not surface [mother 6]. (Gan et al., 2010) Campers felt comfortable telling their stories to a supportive and caring audience and getting answers to their questions, which in turn served as stress relief.(Gillard et al., 2011) Camp administrators are urged to strategically plan for opportunities for	"You can share deep experiences and fears that other people won't understand or don't know how to calm." (Barnetz et al., 2012) "That's got to be really important. Really important. And is through spending time together or talking together, what was it that sort of made that come out? P: Both. And going to the group and talking in the group. Participant # 1 5 - M other - Post-Interview , pg. 2 - 3 (Brodeur, 2005) It (Living Well) has helped me share some of what's inside (me). And the fun activities and fun crafts. I 'm able to let out that part of my childhood that I wasn't fully able to experience. Participant # 10 - III Child - Post-Interview, pg. 2... had a lot of fun. I liked it when we all went off to our own counseling groups, 'cause you got to talk to kids your age and how they felt. I liked the artwork too; that Was fun." Participant #30 - 111 Child - Post-Interview, pg. 4 (Brodeur, 2005) "They take us to Teen Talk, they take us to a quiet place. They	Barnetz et al., 2012, Baruch, 2012, Bignall et al., 2015, Brodeur, 2005, Docherty et al., 2013, Gan et al., 2010, Gillard et al., 2011/16, Hosek et al., 2012, Kirk et al., 2016, Moola et al., 2015, Stewart et al., 2013a, Wolf-Bordonaro, 2003	

Theme: Therapeutic Relationships			
	campers to share concerns and issues about cancer by training counselors to facilitate the discussions. (Gillard et al., 2016) The individual sessions would allow women to ‘‘get things off their chest’’ and provide in-depth discussions with a counselor or therapist. (Hosek et al., 2012) For both groups, the discussion groups provided an opportunity to discuss their feelings...postings expressing feelings of anger were seen as acceptable as long as they were not directed. The DGs provided an outlet for young people and parents to express their emotions. It was apparent that it was seen as a safe space for sharing feelings of isolation, sadness, difference and frustration....For some, the opportunity to express their feelings and frustrations was cathartic in itself as they were able to tell their story to an audience who could understand and relate to their experiences. .(Kirk et al., 2016) In addition to discussing emotions such as anxiety, children dialogued about events – such as hospitalisation and the death of other patients – during unstructured non-activity times at camp...The children appear to discuss a broad range of topics, including events – such as having open-heart surgery or the death of other patients – as well as the myriad emotions that accompany these experiences. Illness storytelling is part and parcel of the camp experience, and they derive pleasure through the process of	don’t force you, they let you get your feelings out. When one person does, you all just let it out.” (Gillard et al., 2011) “…just talking with people, you know it takes the stress off you. Cause other people were aware of your problems and you didn’t always have to keep it inside” (Stewart et al., 2011b)	

	Theme: Therapeutic Relationships	
	listening to others’ stories and sharing their own... (Moola et al., 2015) Third, since these children appear to derive numerous benefits through shared illness storytelling at camp, investigators should research whether there are therapeutic benefits associated with informally dialoguing about illnesses with others at camp...Indeed, research in psychology certainly supports therapeutic talking about difficult experiences in the right context to promote wellbeing (Bandura 1997). (Moola et al., 2015) In the online support intervention, mentors encouraged children to talk about their feelings and support needs.(Stewart et al., 2013a) The support group was a safe place to share feelings....Open communication with other children with asthma and allergies and mentors about feelings and experiences was a new experience for many participants.(Stewart et al., 2013a) presented as relatively well defended in the pediatric unit; yet, given the psychological safe place of the art therapy session, they allowed their emotions to be exposed. (Wolf-Bordonaro, 2003)	

Theme: Therapeutic Relationships			
Cared for/valued online interventions	The response to postings expressing negative emotions displayed empathy, with participants acknowledging and confirming that such feelings were justified. (Kirk et al., 2016)		Kirk et al., 2016

Theme: Therapeutic Relationships				
Development of Trust	Parents thought familiarity with staff members improved children's feelings of trust and security which, if it is the case, highlights the importance of employing permanent members of staff that children can get to know which may promote child coping (Duff, 2003). (Ayres et al., 2011) A good example of this relationship pattern could be seen in one mentee who adamantly refused medical treatment. His mentor, through the relationship he had established with the medical staff, succeeded in bringing the mentee to accepting the required treatment. (Barnetz et al., 2012) The social worker was able to help adolescents establish a trusting relationship with the group leaders due to her longstanding relationship with the families. The involvement of a trusted provider is key to a successful group. (Fair et al., 2012) Facilitators were seen as people who were approachable because of their extensive experience providing "raw" HIV/AIDS education to youth. (Gillard et al., 2011) Many participants appeared to have formed emotional bonds with one another as postings reflected a high degree of intimacy and trust with discussion of personal feelings and relationships. (Kirk et al., 2016) Ease with the treatment setting "That's another part of it (the MMP), the trust factor it creates. She placed a lot of trust in them and she really loved them … And I think because of that she felt safe. She felt she	"We talked about things I didn't believe I'd ever say." (Barnetz et al., 2012) A 17-yearold girl with ALL stated, "When Ty hand is held, feel like l have someone to be my eyes and see me through the LP, then I can trust them to get the needle in the right place." (Weekes et al., 1993)	Ayres et al., 2011, Barnetz et al., 2012, Fair et al., 2012, Gillard et al., 2011, Kirk et al., 2016, Shrimpton et al., 2013, Tiemans et al., 2007, Weekes et al., 1993	Overlap with engaged/accessibility/ safe space

	Theme: Therapeutic Relationships	
	was not going to be let down and that she could go through the process with the people around her.” (Shrimpton et al., 2013) Participants also reported wanting more time together to develop mutual trust and identify issues of concern (Tiemans et al., 2007) Adolescents preferred to have their hand held by a family member such as a parent, a sibling, an aunt, an uncle, or some other relative. When neither parents nor other relatives were available, nurses were next in preference. (Weekes et al., 1993)	

Theme: Therapeutic Relationships		
Trust based on experience	Facilitators were seen as people who were approachable because of their extensive experience providing “raw” HIV/AIDS education to youth. (Gillard et al., 2011) Mentors thought that children could talk to peers in the support group in a different way than their parents. They believed that the support program augmented support from families because mentors and peers provided advice and understanding based on personal experience. (Stewart et al., 2013a) Mentors noted they coached the group and were like older friends who could provide advice and support based on personal experience. (Serlachius et al., 2012)	Gillard, 11, Stewart et al., 2013a, Serlachius et al., 2012
Trust over time	Inherent in this empathic relationship was the need for the program facilitators to build and earn the young women’s trust.(Hosek et al., 2012) The teaching, which also included practical examples of previous success stories, appeared to give them a rationale they could believe in. (Reme et al., 2013) These findings emphasize the important role that health care professionals play in fostering trust and encouraging individuals to take a more active role in managing their illness (Serlachius et al., 2012) Although the children were shy initially, by the third session they had developed trust in the mentors and the group. (Stewart et al., 2013a)	Hosek et al., 2012, Reme et al., 2013, Serlachius et al., 2012, Stewart et al., 2013a

Theme: Therapeutic Relationships				
Empathy	It appears that this important emotional effect was primarily attained in the soul mate relationship pattern, and it seems that this pattern places greater emphasis than other relationship patterns on the first two elements of Spencer’s (2006) division, namely authenticity and empathy: (Barnetz et al., 2012) The importance of camp friendships for youth with chronic illness has been well documented (Bluebond-Langer et al., 1991-Langner et al., 1991). In Bluebond-Langer et al., 1991-Langner et al.’s study, camp relationships for youth with cancer were characterized by qualities of empathy, understanding, and acceptance, and were unlike their relationships with healthy peers. (Gillard et al., 2011) The participants desired program facilitators or interventionists that could ‘‘understand what I’m going through’’ and empathize or ‘‘sympathize’’ with them. (Hosek et al., 2012) The response to postings expressing negative emotions displayed empathy, with participants acknowledging and confirming that such feelings were justified. (Kirk et al., 2016)	One camper explained why camp was different from home: “Because [home is] stressful because you can't do everything everybody else can do, even though you kind of have to. You just need a break. Like it's easier for other people to get stuff done because I fatigue really fast, and here, it doesn't really matter. They'll like, wait up for ya.” (Gillard et al., 2013)	Barnetz et al., 2012, Gillard et al., 2011/13, Hosek et al., 2012, Kirk et al., 2016,	Trust
Theme: I am Not Alone				

Theme: I am Not Alone

Idea for further interpretation/ Third Order Construct	Second Order Construct	Quote	Papers contributing	Acknowledgement of overlap

Theme: I am Not Alone				
The same as others/novel experience: emphasise emotional impact. I am normal?	For example, knowing that feelings of anger, frustration and depression are normal reactions can be reassuring, and can help to reduce the sense of isolation that often accompanies arthritis. (Barlow et al., 1999) This finding highlights one of the advantages of mentors who are facing in their own personal life the same problem as their mentees. (Barnetz et al., 2012) This often overlapped with the theme of the importance of meeting other HIV' young people to share experiences and being reassured that their experience was not unique: (Campbell et al., 2010) felt supported in knowing that other children experienced similar challenges while living with heart defects (Desai et al., 2014) The group provided an opportunity for members to meet other young people living with HIV. (Fair et al., 2012) The first subtheme of forming caring connections was developing awareness of commonalities. (Gillard et al., 2011) Interactions with others who passionately discussed achieving similar personal goals were frequent at camp. (Gillard et al., 2013) Through the combination of interactive activities, icebreakers, and discussions, the young women could ‘‘meet other people who are just like you,’’ which would help them realize that they are not alone. (Hosek et al., 2012)	“Sometimes I thought, ‘Oh God! I’m the only one that has got it [arthritis] out of all my friends’. Then when I watched the video, I knew that quite a lot of other people had got it other than me” (Barlow et al., 1999) “It made me happier, seeing her encourages me, she’s like me and she’s okay, she works… It’s like talking with myself, but it’s not me. (Barnetz et al., 2012) “…liked that we did a kind of bring together activity first, and then I liked the fact that the parents went off without the children. R: Because it gave them time to be alone? P: Uh huh.. .and for them to meet other kids that are like them. They loved (other participant) and (other participant)”. Participant # 1 5 - M other - Post-Interview (Brodeur, 2005) “I feel happier and know that I am not alone and I	Barlow et al., 1999, Barnetz et al., 2012, Brodeur, 2005, Campbell et al., 2010, Desai et al., 2014, Fair et al., 2012, Gan et al., 2010, Gillard et al., 2016/11/13, Hosek et al., 2012, Kashikar-Zuck et al., 2016, Kirk et al., 2016, Lewis et al., 2016, Moola et al., 2015, Marsac et al., 2012, Muskat et al., 2016, Serlachius et al., 2012, Stewart et al., 2013a, Tiemans et al., 2007, White, 2014/16, Wright et al., 2004	Therapeutic relationships/unconstrained

Theme: I am Not Alone	
Social connection is summarised by the phrase ‘you’re not alone’ used by members of all participant groups to express the sense of connectedness young people experienced as a result of meeting others in a similar situation to themselves. (Lewis et al., 2016) Indeed, participating in the DG normalized feelings and experiences further (Kirk et al., 2016) All children suggested that their Camp Willowood social relationships provided them with the opportunity to be the same. Some patients reside in small towns that are located several hundred kilometres from major city centres, and had never interacted with another CHD child. For these participants in particular, the experience of ‘being the same’ was a novel one. (Moola et al., 2015) ...The study also requires researchers and clinicians to think about sick children’s illness identities at home and at camp. While the notion of sick children’s illness identities was not the focus of the study, the majority of youth strongly identified as being ‘the same’ as their peers at camp through relationships based on recognition and affinity.(Moola et al., 2015) HIV-related stigma continues to be present in today’s society and has been recommended as an important focus for health care practitioners in helping children and teens who live with HIV. Living with a	am not afraid anymore. I feel less scared now. I feel not as worried about the future as I did before. I know that I am not the only one with it and that I can do most things that other people can do but just need to be careful. I know that I have somewhere to talk about things, although I can talk to my aunt, it is good to talk to people my age as well and be open about things. I feel better about managing and looking after myself in the future, but know that it will depend on the situation.” (Campbell et al., 2010) One mother stated participation in the group “lets them know that there are other young people out there that are dealing with the same issues that they’re dealing with.” (Fair et al., 2012) Lots of people with brain injury have the same problems as me [teen 4]. My daughter’s reactions

Theme: I am Not Alone

stigmatized condition can bring about a sense of difference and isolation. Group participants indicated that the groups provided a place where they could talk about HIV with others and feel just like everybody else. One younger group participant reported, “You can just have other kids that are like you, you can just sit there and talk with them you could see how they are and are no different than anybody else.” (Muskat et al., 2016) A few participants also made comparisons to diabetes camps to illustrate the benefit of meeting others with diabetes (Serlachius et al., 2012) Feeling “normal” is even more important when one lives with a condition that is often kept secret due to associated shame and stigma. The group was described as helping the participants to feel less different, which is an important part of healthy developmental experience in adolescence. (Muskat et al., 2016) For many children, this was the first time they shared experiences with others who have asthma and allergies. Almost 25% of these children said they did not know any other children with asthma and allergies prior to the intervention, and another 25% said only a few children in their school had asthma or allergies. A few participants noted that although they knew children with allergies, none were as severe as theirs. For	are normal [mother 1] (Gan et al., 2010) “People are just together. You're never alone… It's affected me a lot because I'm probably one of the only people in my school that has sickle cell so it's like, there's not really any people to like connect with or talk about it with. So when you come here it's just really fun to talk to people about it or just even know that the people around you share the same reactions and altercations about it.” (Gillard et al., 2016) “I really liked being with the other girls... I never knew they were going through the same things or... the same problems... knowing someone else feels the same way you do really helped.” (Kashikar-Zuck et al., 2016) One parent stated, “We reviewed the cards and (that helped) him understand that some of the feelings he has are

Theme: I am Not Alone		
	example, a 10-year-old boy with allergies and asthma commented, “There are some people at school that have asthma, but no one with allergies. It feels bad.” Some mentors noted that that they were the only ones with anaphylactic allergies in small schools. For example, when a parent asked one peer mentor how others in her school handled allergies to nuts, she replied, “I’m not sure. I’m about the only one in my school that has severe allergies, so I haven’t really seen how other people deal with it.” ...Mentors reported that the affirmation provided by themselves and group members helped the children believe that their experiences were not unusual... The group experience reinforced that there were other children in similar situations with comparable experiences....They understood that comparison with others helped to normalize their children’s lives. (Stewart et al., 2013a) Some of the other adolescents described being able to meaningfully relate to the issues that others faced. (Tiemans et al., 2007) This would allow their children to realize that others have gone through similar life and health experiences, and to see that other children also have limitations. (White, 2014) These children returned home with reduced anxieties and fears of ‘being the only one’	similar to (other) children here… so he didn't feel like he was alone.” (Marsac et al., 2012) “I kind of feel like everybody else, and that you kind of know them a little bit … you know what they’ve been through and stuff – like going to the hospital a lot and stuff. You don’t really seem to judge them because they are just like you.” (Moola et al., 2015) A more elaborate descriptive quote came from an older teen group participant: “I can compare my life to their life, and they can do the same with me, and they can see what is going on, you know. If they had the same problems that I had or have still, we can go through it together or I can tell them what happened with me and how I got through whatever, or they can tell me what happened with them and how they got through whatever. And

Theme: I am Not Alone		
	with a heart condition. (White, 2014)	it helps a great deal actually … It feels more comfortable talking about some things because like when they ask questions, I’m not the only one there with it. “(Muskat et al., 2016) Affirmational support “As I said, this year before the group started I wasn’t invited to some birthday parties and one of the boys got really mad at me when I asked him to put away a peanut product. So I thought some of the things that were happening to [mentor] were just like mine, where some kids brought peanuts in and he told them to wash their hands. That definitely helped me a lot because I know it was something I could do. (11-yearold girl with allergies)” (Stewart et al., 2013a) “One of the kids had worries about asthma and allergies and by comparing himself to others, he realized he was just the

Theme: I am Not Alone
same as others.” (Stewart13) That was probably one of the best parts, meeting other people who are in the same circumstance. (Tiemans et al., 2007) “‘I feel more brave mommy because I don’t feel like an outcast because I know they’re other kids like me’. That really made a difference for me. I don’t worry—I mean I will always worry about his health but I’m not worrying about how he feels about himself.” (White et al., 2016) Alicia expresses the benefits of her child meeting other children with a similar heart condition: “I think it [meeting other children with CHD] will be fabulous because she’s never met another child – other than when we are down at the clinic – that is in a similar situation to her. And like I said she started telling me just in the year

Theme: I am Not Alone
that she feels a little different.” (White, 2014) Jerry’s father noted that he was more willing to do these things in the DMAP than in other group settings, explaining, “Here, he’s one and the same, on the street he’s different. So here he can let some of his inhibitions down, he is in an environment truly” (Wright et al., 2004)

Theme: I am Not Alone				
Understood/accepted	Children felt that every aspect of JCA and their health-care served to make them look, feel and behave differently from their peers. Consequently, their greatest concerns were for peer belonging and social acceptance. (Barlow et al., 1999) …mentees had been unable to share with anyone before. This strengthens the understanding regarding the importance for coping with the disease of mentors and mentees forming deeper relationships and creating a sense of closeness, that facilitate shared introspection and sharing familiar experiences. (Barnetz et al., 2012) In fact, at camp the children not only found support, understanding, encouragement, and acceptance but also learned more about their disease and its treatment (Bluebond-Langer et al., 1991) A common theme mentioned by all 13 participants consisted of developing social relationships and feeling accepted. (Desai et al., 2014) Establishing meaningful relationships with camping peers were facilitated by (1) campers sharing common challenges they experienced while living with a heart defect; and (2) the acceptance they felt at camp which sharply contrasted their school experience where many felt rejected. (Desai et al., 2014) …reasons given for the ease to form	"Healthy kids make fun of me, At camp, it's okay if you can't do something or don't have hair, No one makes fun of me…"(Bluebond-Langer et al., 1991 Langer) A key finding emerged that participants were conscious of feeling stigmatized because of their heart defect and its associated limitations by peers who did not have a heart defect. One 12-year-old camper reflected while explaining why he returned to camp each year: "You make new friends every year and you get to understand your heart defects with them. I just like hanging out with friends and being able to relate to people cause at my school there is nobody else with heart problems so when I run . . . in the gym I can't really relate, nobody can relate to me, they are like 'are you slowing down?' But at camp, when I am tired they	Barlow et al., 1999, Barnetz et al., 2012, Bluebond-Langer et al., 1991, Desai et al., 2014, Gillard, 11, Lewis et al., 2016, Muskat et al., 2016, Stewart et al., 2011b/13, Tiemans et al., 2007,	Therapeutic relationships.

	Theme: I am Not Alone	
	connections and feel accepted was that at camp, everyone dealt with the same issues related to HIV: (Gillard et al., 2011) Young people in both the new ChIPS Member's group and the ChIPS Reference Group spoke of being connected with other ChIPS members whether they were new to ChIPS or had been members for some years. [My school friends] can be supportive, they're so supportive, and they're really, really amazing at that, but it's not the same as meeting someone who's actually been through it. (New ChIPS Member group) It's good having people that understand. … We're able to joke about [our illness] and talk comfortably about it and not have to worry about what we're saying or who we're talking to because everyone in the group gets it. (ChIPS Reference Group) (Lewis et al., 2016) a sense of safety, acceptance, and comfort as a result of their participation in the program. (Muskat et al., 2016) Many children indicated that they finally felt accepted as part of a group of peers. (Stewart et al., 2013a)	are like 'oh I understand', so it helps a lot". (Desai et al., 2014) while equating the level of acceptance he felt at camp as: 'It makes you feel close to home, like a home away from home.' (Desai et al., 2014) "I think everyone is really accepting of one another because we have something so strong in common that it just gave us that connection, like something to be able to talk about that we can't talk about with everyone." (Muskat et al., 2016) One felt "more accepted, 'cause..I knew I had friends on the Internet. Especially in junior high, 'cause I was the only one that was really "different," and now I know that I have someone else" [Stewart et al., 2011b) We understand what we are going through (Tiemans et al., 2007)

		Theme: I am Not Alone	
Belonging/connectedness	described a close, comfortable connection and sense of belonging with other participants that appeared very similar to the curative factor defined by Yalom (1995) as cohesion, which defines a sense of solidarity amongst group members. (Brodeur, 2005) External outcome themes centered on concepts related to social interactions, feelings of community, and shared experiences among the children. These subthemes included importance of friendship, inclusion in a peer group, fun, and feelings of safety. (Bultas et al., 2015) At camp, participants experienced a sense of relief, normalcy and belonging, and felt supported in their interpersonal interactions with peers. (Desai et al., 2014). For the two boys, their sense of belonging arose from connections they had with counselors, not other campers. (Gillard et al., 2011) Social connection is summarised by the phrase 'you're not alone' used by members of all participant groups to express the sense of connectedness young people experienced as a result of meeting others in a similar situation to themselves. Social proximity tended to unite campers. Several staff and camper interview participants referred to how camp traditions such as chants, cheers, and annual special events encouraged bonding and feelings of	"And it's okay to be sick. It's not a shameful thing. Like a lot of times I feel ashamed that I'm sick. Or embarrassed. I think Living Well's helped a lot as far as.. .Like, I don't like to meet new people 'cause I don't want to have to explain the whole thing. But for some reason, it's like when you're around other people who are dealing with illnesses, you don't have to explain anything. They don't necessarily know about the disease, but they know that eventually you'll come around and say what's going on. It's like we have our own language. It's like your own etiquette." (Brodeur, 2005) "…When I found out I was upset. I felt alone, I felt upset. When I started attending the sessions I met others with the same condition. I felt part of a group. Now I know there are others with the same condition. "(Rita, 14	Brodeur, 2005, Bultas et al., 2015, Campbell et al., 2010, Desai et al., 2014, Gillard et al., 2011/13/16, Hosek et al., 2012, Moola et al., 2015, Lewis et al., 2016, Muskat et al., 2016, Nicholas et al., 2007, Stewart et al., 2013a, Tiemans et al., 2007, White, 2014/16

	Theme: I am Not Alone	
	unity, and these traditions were also observed during camp. For example, after breakfast every morning, an aerobics session was conducted in the dining hall in which the whole camp gathered closely near the stage, danced, and sang along as a group to songs emceed by dynamic and animated camp staff....The special bonds that emerged between participants experiencing cancer were also evidenced by remarks about being valued by a caring community. A Junior Counselor shared that: Friends at home don't really understand the whole bond between two cancer patients. It's there because you went through it together and you know what it's like. And a friend at home doesn't truly understand how the hospital works and how chemo works and how the IV pole works. But the camp friends do...The emotional support and connections developed in camp support what Ryan and Deci (2000) term relatedness. Relatedness refers to feeling securely connected and valued by others, where one feels as if they belong to a larger social “whole” (Gillard et al., 2013) A camper identified a sense of belonging as one of the driving forces determining what camp means to him. (Gillard et al., 2016). The group meetings would promote social bonding and young women ‘‘might even get some friendships out of it.’’ (Hosek et al., 2012)	“I used to think that I was the only one in the world who had a heart problem and when I found out about heart camp I was thinking, wow maybe I was wrong . . . I did not feel like I was an outcast anymore . . . it felt good”. (Desai et al., 2014) At camp, participants experienced a sense of relief, normalcy and belonging, and felt supported in their interpersonal interactions with peers. A 16-year-old camper summarized, “What camp means to me is being away from all of my problems and to be with people that have been through the same thing that I have” (Desai et al., 2014) “Being around many other people who were bald, missing limbs, or spent time at the cancer hospital, facilitated the campers' comfort, self-regard, and social connections.” (Gillard et al., 2013)

Theme: I am Not Alone	
Young people in both the new ChIPS Member's group and the ChIPS Reference Group spoke of being connected with other ChIPS members whether they were new to ChIPS or had been members for some years. [My school friends] can be supportive, they're so supportive, and they're really, really amazing at that, but it's not the same as meeting someone who's actually been through it. (New ChIPS Member group) It's good having people that understand. … We're able to joke about [our illness] and talk comfortably about it and not have to worry about what we're saying or who we're talking to because everyone in the group gets it. (ChIPS Reference Group) In contrast, the children's camp-based social relationships help them to forge a sense of belonging and inclusion...Much like looking in a mirror in which the self is reflected back to view, meeting other children with similar conditions forged a sense of affinity. (Moola et al., 2015) Based on statements made by older children and adolescents, video conferencing and the chat room were seen as meaningful and integral activities augmenting their social connection with a peer group...Some participants felt that the opportunity to talk with peers was a crucial feature of the network. Children enjoyed connecting with peers with a similar condition; an opportunity that, for some, was largely	"People are just together. You're never alone… It's affected me a lot because I'm probably one of the only people in my school that has sickle cell so it's like, there's not really any people to like connect with or talk about it with. So when you come here it's just really fun to talk to people about it or just even know that the people around you share the same reactions and altercations about it." (Gillard et al., 2016)) "She really enjoyed it. She liked connecting with other kids that have allergies. She does know other kids here in [city] that do, but not necessarily getting to know them as they have in this program that you put together. They really got to know each other." (Stewart et al., 2013a) This is illustrated by some of the participants' comments: "Everyone was going through the same

Theme: I am Not Alone			
	unavailable (e.g., children with rare conditions; children in isolation). (Nicholas et al., 2007)	experience and we didn’t feel . . . singled out.” (Tiemans et al., 2007) “I feel more brave mommy because I don’t feel like an outcast because I know they’re other kids like me’. That really made a difference for me. I don’t worry—I mean I will always worry about his health but I’m not worrying about how he feels about himself. (White et al., 2016) He said overall just walking away from the trip – he feels better. He feels he has more courage just being at school because he knows that he’s not the only one. And he doesn’t feel like an outcast anymore and that was very encouraging to me … Yeah and I think what helped was he saw that everyone had a common scar – a big scar on the chest. And yeah it really helped him not feel insecure and not to feel like an outcast – that’s the term that he used” (White,	

Theme: I am Not Alone

2014)

Theme: I am Not Alone				
Connectedness and belonging through sharing experiences leading to reduced isolation	However, there was consensus that showing children talking about their own experiences of JCA helped both children and parents to feel less isolated, and was seen as a major benefit of this particular video. (Barlow et al., 1999) The mentors sharing their difficulties with the mentees frequently dispel fears and loneliness. (Barnetz et al., 2012) One of the related benefits of having a form of narrative medicine was further described by an artist (5) as the children can “see other children’s beads and relate to the treatment they have been through.” (Baruch, 2012) External outcome themes centered on concepts related to social interactions, feelings of community, and shared experiences among the children. These subthemes included importance of friendship, inclusion in a peer group, fun, and feelings of safety. (Bultas et al., 2015) Reduced isolation (Campbell et al., 2010) Establishing meaningful relationships with camping peers were facilitated by (1) campers sharing common challenges they experienced while living with a heart defect; and (2) the acceptance they felt at camp which sharply contrasted their school experience where many felt rejected.(Desai et al., 2014) helped AYA connect with others, and led to meaningful conversations..	“The connection was great, I felt wonderful at the meetings, the mentor told me about his experiences from the past, it’s like what’s happening to me and I feel a sense of a shared fate.”(Barnetz et al., 2012) “Some of the other people had some of the same feelings that I had that I can share with. We all had something in common and stuff like that.” (Brodeur, 2005) “We as a family were able to come together to better understand my brain injury and how I live my life.” (Gan et al., 2010) “Because of Teen Talk, campers had a sense that they were not alone and that there were others like them: “I can relate to them and we relate to each other” (Gillard et al., 2011) Getting to know other people with fibromyalgia around my age was nice. I liked learning the exercises in a group format... I liked knowing that I wasn't the	Barlow et al., 1999, Barnetz et al., 2012, Baruch, 2012, Brodeur, 2005, Bultas et al., 2015, Campbell et al., 2010, Docherty et al., 2013, Desai et al., 2014, Fair et al., 2012, Gan et al., 2010, Gillard et al., 2011, Kashikar-Zuck et al., 2016, Kirk et al., 2016, Moola et al., 2015, Muskat et al., 2016, Nicholas et al., 2007, Reme et al., 2013, Stewart et al., 2011b/13, Tiemans et al., 2007, Whittemore et al. 2010	Link to idea not having to be the same/enjoying discussing differences under unconstrained

	Theme: I am Not Alone	
	Many reported positive changes in AYA ability to communicate “previously unspoken thoughts” and renewed interest in social connections. (Docherty et al., 2013) Benefits described in the current study, including receiving support and the desire to share their experiences with others, (Fair et al., 2012) Besides having HIV, the other major commonality between campers was that they needed to adhere to a strict medication regimen. The camp director mentioned that campers felt connected with similar others because they saw “143 other campers taking medications right alongside of them.” (Gillard et al., 2011)Campers created connections with others by taking interest in their lives, sharing their struggles, and providing encouragement to others to succeed. (Gillard et al., 2011) Many participants appeared to have formed emotional bonds with one another as postings reflected a high degree of intimacy and trust with discussion of personal feelings and relationships. (Kirk et al., 2016) Dialoguing with other children at camp about aversive experiences was the central mechanism through which children established a sense of belonging. (Moola et al., 2015) The bonds among group members were described by them as close, almost family-like, enhanced by shared medical	only one confused or… wasn't the only one that wasn't that excited about learning this really complicated exercise.(Kashikar-Zuck et al., 2016) Noah provides an example of a strand of CHD related camp dialogue with other children …”‘how many scars do you have? I have this one and this one! Oh cool! Did it hurt?’ Sophia echoes Noah’s sentiments by suggesting that ‘we definitely talked about where we have scars, which is a popular topic at Camp Willowood, apparently. Definitely what medications we had’.” (Moola et al., 2015) “Talking to kids that have the same problems as you, things that your friends don’t understand. It’s nice to make friends ...I have a friend on the chat line and video conferencing.” (Nicholas et al., 2007) Unlike other treatments where you can openly

Theme: I am Not Alone		
	experiences. (Muskat et al., 2016) As a result of SBW, relationships emerged or were strengthened, from which patients derived meaningful support. In summary, this support came from multiple sources including online peers, in-hospital ‘playroom’ peers, and family members. These various supports each had been positively influenced, in varying ways, toward support facilitation by engagement with SBW.(Nicholas et al., 2007) In this intervention, children loved talking to “children like me.” Children indicated they were more relaxed because there were other kids like them, which they found, “comforting” and “soothing.” (Stewart et al., 2013a) Beyond meeting others, adolescent participants highly valued the opportunity to socialize and become acquainted with one another. Developing close relationships with peers who understood elements of a teen’s experience with a CFD reportedly allowed for more open discussion and allowed adolescents to constructively and supportively address issues they would seldom discuss with peers. (Tiemans et al., 2007)	share your treatment experiences with other people, participants undergoing the Lightning Process are specifically encouraged not to talk to anyone about it. One of the participants describes it like this: “…and also because you are not really supposed to talk about it with other people, is what he said, because it only confuses you and them. You don’t have anyone to talk to about it with so you feel kind of alone” (Reme et al., 2013) Fourteen adolescents reported that they could talk to others with similar experiences. “When I was doing the chats, I was involved with the conversation, and I wasn’t thinking about [loneliness].” “[The chats] made me realize that I’m not alone; like with my disability .there’s lots of people out there that go through the exact same thing as I do”

Theme: I am Not Alone
[CP-04] (Stewart et al., 2011b) “She loved it. She was really keen, she always wanted to be home for it so we would change our weekend schedule because it was important to her. She loved the relationships she developed with the other children. It was nice to see her reach out to a community affected by similar health issues and talking to people who knew what it is like living with the constraints that she has to live with.” (Stewart et al., 2013a) “The camp did help with that [to talk about our different experiences] by bringing us all together and letting us get to know each other for a couple of days so that we felt that we were comfortable enough to go up to each other and just talk about it (CFDs).” (Tiemans et al., 2007) “She added, “I could relate [to the characters] because all of them made points

Theme: I am Not Alone			
	that I feel I have.” (Whittemore et al. 2010)		
	“‘But really I felt so kind of	Barlow et al.,	Link with idea of being the

Theme: I am Not Alone				
Not alone	However, there was consensus that showing children talking about their own experiences of JCA helped both children and parents to feel less isolated, and was seen as a major benefit of this particular video...For example, knowing that feelings of anger, frustration and depression are normal reactions can be reassuring, and can help to reduce the sense of isolation that often accompanies arthritis. (Barlow et al., 1999) It was further found that for many mentees the relationship with the mentor broke down the wall of emotional isolation, especially through the experience of sharing (at times mutually) emotions, experiences, difficulties, and concerns that the mentees had been unable to share with anyone before. The experience of breaking emotional isolation as a result of the encounter with their mentors can inform on the social world of diabetic adolescents and the sense of isolation they experience with medical staff, parents and peer groups The mentors sharing their difficulties with the mentees frequently dispel fears and loneliness.(Barnetz et al., 2012) Program as a Sense of Community Leading to Not Feeling Alone Several of the participants talked about how meaningful it was to meet people in similar situations as theirs, and to be able to see that they were not alone in their experience. (Brodeur,	isolated and alone with it, that I think going through all that [the sessions] was a great support for me as much as anything else” (P 4 2 PE). (Dennison et al., 2010) Participants remarked that it was helpful to be with other HIV' young people. Most participants mentioned that it was helpful being part of a group in which difficult explanations about status were not required and where there was no secrecy: “I feel happier and know that I am not alone and I am not afraid anymore” (Campbell et al., 2010) One mother stated participation in the group “lets them know that there are other young people out there that are dealing with the same issues that they’re dealing with.” (Fair et al., 2012) “I wouldn't want to be doing it on my own... because you wanna have	1999, Barnetz et al., 2012, Brodeur, 2005, Campbell et al., 2010, Curle et al., 2005, Dennison et al., 2010, Desai et al., 2014, Fair et al., 2012, Gan et al., 2010, Gillard et al., 2011, Hosek et al., 2012, Kashikar-Zuck et al., 2016, Kirk et al., 2016, Moola et al., 2015, Nicholas et al., 2007, Stewart et al., 2011b/13, Tiemans et al., 2007, White et al., 2016, Whittemore et al. 2010	same

	Theme: I am Not Alone	
	2005) The most frequently cited and important benefit of the group identified by both children and parents was a reduction in feelings of isolation (Curle et al., 2005) All participants felt that they learned valuable information and were reassured that they were not alone in their situation. Results suggested that creative writing groups can promote personal growth and decreased isolation of adolescents living with HIV. (Fair et al., 2012) (Gan et al., 2010) At home, campers might have been the only ones in their households taking medications. At camp, they saw most other campers taking them as well, which highlighted that they were not alone. (Gillard et al., 2011) Through the combination of interactive activities, icebreakers, and discussions, the young women could ‘‘meet other people who are just like you,’’ which would help them realize that they are not alone. (Hosek et al., 2012) Participants expressed reassurance from knowing others shared their experiences and feelings.(Kirk et al., 2016) Reducing isolation by exposing children to others who share a similar biography has been reported by other researchers and may be another central process through which camp benefits sick children (Goodwin and Staples 2005, Gillard et al. 2011). (Moola et al., 2015)	other people in the group cause you know that there's other people out there that are just like you and you also learn from their experience.” (Kashikar-Zuck et al., 2016) Moreover normalization of feelings was evident as participants emphasized that individuals were not alone in experiencing such feelings. “Hey, You are certainly not alone! I think everyone with CF has felt like tha sometimes. I know for a fact I hve felt like why do I bother but I tend to do it when i’m well bcoz i cant see any difference when i take my tablet sna if i miss them but I’ve learnt now that i have to do my nebs and stuff” (Young person DG) (Kirk et al., 2016) Jayden echoes the other children by stating that ‘it makes me understand that you’re not alone, there’s other people, that are in similar situations that can understand and also, my

Theme: I am Not Alone			
	Children confirmed that they felt less alone and more like other children following the online support program. (Stewart et al., 2013a) Children, parents, and mentors believed that the online peer support group helped the children to realize they were not alone and that children enjoyed talking to peers about their experiences and coping strategies. (Stewart et al., 2013a) Parents also identified benefits of peer interaction for their children. They noted the importance of teens having opportunity to speak with peers who had encountered similar conditions and specific realities. Benefits included decreased isolation and stigma and increased normalization and camaraderie as illustrated in the following statements: “She was one of a number of people who have had to have things like this (surgeries).” (Tiemans et al., 2007)	friends won’t understand as well as people at Camp Willowood will’. (Moola et al., 2015) Another older child similarly commented, “. . . I wanted to hear what the other hospitals were like and it makes you feel like you’re not the only one who is in the hospital and sick.” (Nicholas et al., 2007) but mainly they got to interact with others. Because they might not have other kids with asthma and allergies in their classes or their school. They won’t feel so alone. Like there are 300 or 400 kids in my school and I am the only one with severe allergies. They got to learn from my experiences. (Female Mentor, 15 years of age) (Stewart et al., 2013a) A parent appreciatively said, “to have someone that they can talk to, and that is sort of their age and there with them [is of] tremendous benefit for	

Theme: I am Not Alone
them.” (Tiemans et al., 2007) A 16-year-old male attending camp for the fifth year voiced, “I used to think that I was the only one in the world who had a heart problem and when I found out about heart camp I was thinking, wow maybe I was wrong . . . I did not feel like I was an outcast anymore . . . it felt good” (Desai et al., 2014) Fourteen adolescents reported that they could talk to others with similar experiences. “When I was doing the chats, I was involved with the conversation, and I wasn’t thinking about [loneliness].” “[The chats] made me realize that I’m not alone; like with my disability .there’s lots of people out there that go through the exact same thing as I do” [CP-04] (Stewart et al., 2011b) “It is a good opportunity to

Theme: I am Not Alone				
		share experiences and realize that you are not alone” (Tiemans et al., 2007) Another teenager stated, “I felt like you could open up. This program lets teenagers open up…. Kids don’t feel like they’re alone when they answer the questions.” (Whittemore et al. 2010) “‘I feel more brave mommy because I don’t feel like an outcast because I know they’re other kids like me’. That really made a difference for me. I don’t worry—I mean I will always worry about his health but I’m not worrying about how he feels about himself.” (White et al., 2016)		

Theme: Emotional and Informational Support				
Idea for further interpretation/ Third Order Construct	Second Order Construct	Quote	Papers contributing	Acknowledgement of overlap

Theme: Emotional and Informational Support				
Informational Support (Communicated via another person)	The mentees reported that they were able to use their mentors’ help to solve specific problems. Some spoke about instrumental problems (the link with agencies), (Barnetz et al., 2012) The children indicated that friendships with other cancer patients were an important source of information about various cancers, procedures, and treatments. They looked to other young patients for information to prepare themselves for what might happen...The children exchanged information, not only about medical issues, but also about how to cope with their disease and it calment. (Bluebond-Langer et al., 1991) They felt that the educative aspect of the LFP helped them to understand the health benefits of medication, and tended to stress these rather than side effects or adherence difficulties (Campbell et al., 2010) Campers also shared ideas to cope with their challenges such as ways to manage teasing related to their surgical scars. Ten participants also reported that the informal heart-related educational activity led by the cardiologist was meaningful for them Nutrition education activities planned under the guidance of a dietitian were valued. In addition, they learned more about their cardiac condition (Desai et al., 2014) a safe place to talk openly about their experiences, which not only served to deepen their understanding of their illness, but also resulted in increased support.	“I can just ask them, "What's it like? What do you have to go through?' They also saw themselves as able to give information to help other children. As one female, age 12, pointed out, "Well, Kim is on the kind of therapy now that just finished, so now she can come to me and ask me what it's like, and I can tell her.'2 (Bluebond-Langer et al., 1991) A 12-year-old female stated, ‘I have learned to eat healthier because before I came to camp I used to eat up a lot of junk food. And I still do, but I keep myself on a diet kind of like.’ (Desai et al., 2014)A 71-year old father stated his son “is more outspoken because, before, he wouldn’t talk about things. And we had to explain to him, you know, you have to take your pills. Now he understands more by talking to other people.” Another mother said, “They gained a lot of experience because in the writing group they got to see a lot of	Barnetz et al., 2012, Bluebond-Langer et al., 1991, Campbell et al., 2010, Desai et al., 2014, Fair et al., 2012, Gan et al., 2010, Gillard et al., 2011, Hosek et al., 2012, Kashikar-Zuck et al., 2016, Kirk et al., 2016, Muskat et al., 2016, , Serlachius et al., 2012, Stewart et al., 2011b, Stewart et al., 2013a, Wolf-Bordonaro, 2003	Freedom from adult rules (Unconstrained), Managing Myself (Resilience)

	Theme: Emotional and Informational Support		
	Issues such as taking medications during a sleepover, telling a teacher not to help clean a cut knee, and disclosing to a potential sexual partner were discussed. Advice was shared between teens on how best to handle these difficult situations. (Fair et al., 2012) All participants felt that they learned valuable information (Gan et al., 2010) Campers discussed how they often learned from others taking the same kinds of medications effective ways to take their medications and how to deal with side effects. (Gillard et al., 2011) The participants also reported that interventions developed for young women living with HIV should devote time to disclosure. Specifically, teaching young women ‘‘how to disclose and who to tell’’ by improving communication and learning to evaluate the risks and benefits of disclosure to others. (Hosek et al., 2012) Although the young people posted queries relating to the management of medications/therapies, They exchanged experientially derived advice and views on their strategies for managing treatments, emotions, relationships, identity and support from services, often giving detailed descriptions of how they had personally managed different situations...Some young people were experiencing bullying at school, and participants responded to these	different forms of writing and a lot of different ways of expressing how you feel through writing.” (Fair et al., 2012)I thought I was doing it right, “but she showed me how to do it and it was helpful 'cause it felt different.” (Kashikar-Zuck et al., 2016) “I found it really really helpful when we’re having the discussions with the other diabetic kids and learning from their mistakes and you know talking about what they found useful and communicating with each other and using each other’s ideas.” (Girl, 14 years) (Serlachius et al., 2012) “Just before the group happened, I was feeling left out of things, but when we did the trial, I got to know there was other people and when we had a meeting we told each other about our experiences. I remember one week we got to share about other people’s experience and how they got to handle it and I really liked to hear how they handled it	

	Theme: Emotional and Informational Support	
	postings by sharing their own experiences and advising on different strategies to manage this situation. (Kirk et al., 2016) help members find solutions to practical issues (i.e., disclosure strategies and relationship challenges), and...And most positively, the group participants themselves credited the group for enhancing their knowledge of HIV and their treatment adherence (Muskat et al., 2016) Participants suggested increasing peer interaction in the programme, and swapping ideas on how to manage problems. (Serlachius et al., 2012) discussing coping strategies to help with diabetes-specific problems and stressors, (Serlachius et al., 2012) They discussed session topics, and understood their family more. “It just showed me how other people deal with their family members and kind of helps me.” (Stewart et al., 2011b) or talking to friends or their teacher about their asthma/allergies. Children thought that the support group filled some gaps in their knowledge. (Stewart et al., 2013a) educated subjects about sickle cell disease, (Wolf-Bordonaro, 2003)	and the next time it happened to me, I tried using their methods.” (11-year-old girl with allergies) (Stewart et al., 2013a)

Theme: Emotional and Informational Support				
Emotional Support	A good example of this relationship pattern could be seen in one mentee who adamantly refused medical treatment. His mentor, through the relationship he had established with the medical staff, succeeded in bringing the mentee to accepting the required treatment. (Barnetz et al., 2012) Another explanation is that for low income African-American youth, simply interacting with the research team and learning about asthma management had an immediate calming effect. (Bignall et al., 2015) Recognition, validation and emotional support were almost always cited as important. (Dennison et al., 2010) Another camper recalled that having his cardiologist as his 'roommate' the first year he came to camp helped him cope better with homesickness (Desai et al., 2014) The interaction with a group of HIV-positive peers provided them with a safe place to talk openly about their experiences, which not only served to deepen their understanding of their illness, but also resulted in increased support. (Fair et al., 2012) Campers felt comfortable telling their stories to a supportive and caring audience and getting answers to their questions, which in turn served as stress relief... Emotions tended to run high during Teen Talk. This was one of the few (if not the only) places that campers had a caring group with whom to discuss their feelings (Gillard et al.,	"You can share deep experiences and fears that other people won't understand or don't know how to calm." (Barnetz et al., 2012) "Helped us to discuss concerns and feelings that otherwise might not surface [mother 6]."(Gan et al., 2010) A 15-year-old camper discussed how camp made her feel: "You're just always getting reassured that it's okay that you have this [HIV], and it's just a good feeling." (Gillard et al., 2011) Camp provided resources for alternative attitudes toward dealing with problems. A 14-year-old camper discussed how camp helped him: "When I used to get angry, I just handle matters myself. I'd get in trouble. Here I don't get in trouble. They just talk to me for a while, about like, how it's not worth it." (Gillard et al., 2011) Mostly I think they got emotional support. They	Barnetz et al., 2012, Bignall et al., 2015, Dennison et al., 2010, Desai et al., 2014, Fair et al., 2012, Gan et al., 2010, Gillard et al., 2011/13, Kirk et al., 2016, Muskat et al., 2016, Nicholas et al., 2007, Stewart et al., 2011b/13, Weekes et al., 1993	Connectedness, Therapeutic Relationships (emotional release)

	Theme: Emotional and Informational Support	
	2011) The emotional support and connections developed in camp support what Ryan and Deci (2000) term relatedness. Relatedness refers to feeling securely connected and valued by others, where one feels as if they belong to a larger social “whole” (Gillard et al., 2013) They exchanged experientially derived advice and views on their strategies for managing treatments, emotions, relationships, identity and support from services, often giving detailed descriptions of how they had personally managed different situations.. (Kirk et al., 2016) Moreover, the groups helped the attendees to cope with the stigma associated with HIV and in providing support for improved medication adherence. (Muskat et al., 2016) Accordingly, all participants stated that online participation offered psychosocial support to hospitalized children.. Finally, the replication of earlier findings in the literature strengthens the contention that this type of online intervention potentially contributes to important child health outcomes such as enhanced self-esteem and reduced depression (Nicholas et al., 2007) However, adolescents felt the intervention helped them deal with negative feelings and be more patient and happy (Stewart et al., 2011b) Children recognized that emotional support, having a safe place where they could talk to others, share fears and	could talk about what they had done in the group. I think they got to learn some new strategies with the role playing, but mainly they got to interact with others. Because they might not have other kids with asthma and allergies in their classes or their school. They won’t feel so alone. Like there are 300 or 400 kids in my school and I am the only one with severe allergies. They got to learn from my experiences. (Female Mentor, 15 years of age) (Stewart et al., 2013a) Two teens explained: “just talking with people, you know it takes the stress off you. Cause other people were aware of your problems and you didn’t always have to keep it inside” (Stewart et al., 2011b)

Theme: Emotional and Informational Support		
	triumphs, and receive encouragement were key components in this online support intervention. Both boys and girls spoke about being supported emotionally by the group and feeling for the first time that they could be honest about their feelings and could talk about the problems they encountered. (Stewart et al., 2013a) A 17-year-old boy with rhabdomyosarcoma stated, "When my hand is held, know somebody is there, and so l am more like peaceful and feel more secure." One 12-year-old boy indicated that if he did not have someone to hold his hand, he became "jumpy" and nervous, (Weekes et al., 1993)	
Theme: Improved Relationships		

Theme: Improved Relationships				
Idea for further interpretation/ Third Order Construct	Second Order Construct	Quote	Papers contributing	Acknowledgement of overlap
Improved relationships with family (including improved communication/empathy)	Furthermore, some clinicians indicate how the BOC Program, as narrative medicine, is useful in practice to "provide good talking points for the kids…teens start conversation because of their beads" and it is used to "open up communication with families...to get even quiet kids to start to talk." (Baruch, 2012) Impact of Living Well on family cohesion. Several participants talked about how they felt the program had brought their family closer together. (Brodeur, 2005) From parents' perspective, the TMV intervention provided a way for AYAs to express their often difficult-to-describe experiences to friends and family: My feeling was of him trying to express himself, as far as what he had been through, in words from a song. (Father; son, 21 years old) (Burns et al., 2010) Power of the intervention to enhance connectedness among AYA, healthcare providers, family, and friends, centered on how the intervention fostered important relationships between AYA and others who could provide support and help. Parents repeatedly reflected on the synergistic benefits experienced by family when the intervention helped their AYA with relationships. Subthemes (Table 3) included: how the intervention enhanced	Parent (H) wrote, "Storytelling…tangible way to look at and tell their story," while parent (E) wrote, "she gets to share her story, other people really get to see." (Baruch, 2012) This theme outlines what participants hoped to get out of the Living Well program. "I'd like to unleash some creativity. We've done things together. We did a ceramic glazing - what is it called in Richmond, all fired up? We did a bowl there for my parents for Christmas one year. And everybody got to do a little part of it. And that was good and we got to work together. That was fun. You learn a little bit more about each other and maybe let your guard down a little bit. Even though we're a family and we stay together, a lot of times we keep invisible shields up SO we won't hurt anybody's feelings." (Brodeur, 2005) "When I I watched the video, it was like he was	Baruch, 2012, Brodeur, 2005, Burns et al., 2010, Docherty et al., 2013, Fair et al., 2012, Gan et al., 2010, Jaser et al., 2014, Lewis et al., 2016, Marsac et al., 2012, Nicholas et al., 2007, O'Callaghan et al., 2013, Serlachius et al., 2012, Shrimpton et al., 2013, Sibinga et al., 2011, Stewart et al., 2011b, Stewart et al., 2013a, Wright et al., 2004	Emotional Support

<table>
<tr><th colspan="3">Theme: Improved Relationships</th></tr>
<tr><td></td><td>AYA connectedness with health care providers, parents, and family members; (Docherty et al., 2013)
All guardians described better communication between themselves and their child in the home. Some guardians explained that although increased conversations were not centered on the group, adolescents were more talkative in general. (Fair et al., 2012)
The adolescents with ABI and their family members noted that they enjoyed being in the sessions together and having the opportunity to share and interact with each other openly. They commented that this opportunity had not presented itself before and they appreciated the honest dialogue that occurred (Gan et al., 2010)
One adolescent stated that the study ‘‘helped relationships within the family because everyone became more positive.’’ (Jaser et al., 2014)
Parents who participated in each of the focus groups experienced the satisfaction of seeing their offspring’s enthusiasm for ChIPS. They also identified other benefits of the Introductory Program including the chance to enjoy time with their young person protected from intrusions during the commute, and to pursue their own interests (Lewis et al., 2016)
Parents also reported learning about common reactions and experiences</td><td>trying to explain to me or everybody that watched it what he’s been through....” (Father; son, 21 years old) (Burns et al., 2010)
“In the midst of all that havoc brought on by the illness, it just brought us together as a family, and it was a project that we all focused on; it gave us all something.” (Mother; son, 13 years old) (Burns et al., 2010)
A 58 year-old mother explained changes in her daughter’s ability to communicate this way, “And after coming home, after the writing classes and stuff, the conversations about meeting someone else was even different because they had never been exposed to that type of stuff before. It was really good.”
one 45-year old mother said, “She opens up more to her mother and her family. She used to be pretty shy, but now she’s like so talkative!”
A 71-year old father stated his son “is more outspoken because, before, he wouldn’t talk about things. And we had</td></tr>
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Theme: Improved Relationships			
	among families facing pediatric cancer and ways to promote communication about cancer within the family. For example, one parent noted, “(The Cellie Kit) helped him formulate questions so (that I could) understand exactly what he was looking for.” Similarly, one parent commented, “(The Cellie Kit) made us more comfortable talking about (cancer) with him. (Before receiving the Cellie Kit), there were a lot of things we probably wouldn't talk about.” (Marsac et al., 2012) As a result of SBW, relationships emerged or were strengthened, from which patients derived meaningful support. In summary, this support came from multiple sources including online peers, in-hospital ‘playroom’ peers, and family members. These various supports each had been positively influenced, in varying ways, toward support facilitation by engagement with SBW. (Nicholas et al., 2007) accompaniment Leila calmed, stopped crying, displayed regulated breathing, a brighter mood, and increased engagement with others. Her mother also found the music “calming” as she rocked Leila in her arms...enable their connectedness with supportive figures, (O'Callaghan 13) (1) conflict resolution was added to the communications skills training module specifically to address the issue of	to explain to him, you know, you have to take your pills. Now he understands more by talking to other people.” (Fair et al., 2012) “Mom was over-protective after my injury because she was worried about me [teen 5]. .. . that my mom and dad get stressed out too and I learned some things to try to calm down when I am frustrated” (Gan et al., 2010) Sharing radiotherapy experiences with extended family and family friends “Being able to send a copy of the DVD to America for the family to see was just awesome. They understood what was happening and they could see she wasn’t afraid. They could see she was coping. So the family fear was not there when they called to talk to us. It was a huge positive spin off.” (Shrimpton et al., 2013) P: Yeah, like with me and my mom. We used to argue all of the time, but now we don’t. Now we just talk it out. I: What changed as far as that situation? P: Me and my mom	

Theme: Improved Relationships

	parent/adolescent conflict; (Serlachius et al., 2012) With regard to interpersonal relationships, most participants reported being able to get along better with family and friends by being more aware of their stress and in turn reducing their reactivity and hostility toward others. (Sibinga et al., 2011) While communication changed, most adolescents denied effects on family relationships.(Stewart et al., 2011b) Perceived support from family and friends and support seeking coping increased following the intervention. (Stewart et al., 2013a) For the younger participants and those with higher cognitive impairments, the development of appropriate social skills was frequently noted. (Wright et al., 2004)	got a better relationship. I: Why do you think that changed? P: Because I just—when I'm stressed, I get real angry over the littlest things. Now that I'm not stressed anymore, I can talk to my mom better. (Sibinga et al., 2011) The teens learned strategies for communicating. "Certain things that I've talked about in the peer group, I'm talking about it more in my family; I'm not keeping things to myself" (Stewart et al., 2011b) They discussed session topics, and understood their family more. "It just showed me how other people deal with their family members and kind of helps me." (Stewart et al., 2011b)	

Theme: Improved Relationships			
Alternative focus/more than just ill child	The TMV intervention provided experiences that transcended distance. There was a positive anticipation for family involvement, with the entire family often contributing (Burns et al., 2010) Further, blood glucose monitoring is one of the most common sources of conflict between adolescents and parents…and family communication often focuses on diabetes care. In the PA intervention, we attempted to take some of the focus of parent-child communication away from diabetes management by asking parents to provide positive affirmation statements to adolescents. (Jaser et al., 2014) One adolescent viewed the network as a means of introducing something innovative, interesting or fun to others in his family. (Nicholas et al., 2007) Music therapy can enable catharsis, self-expression, diversion, distraction from symptoms, and invasive procedures, aesthetic experience, a sense of achievement, important communication, and, very importantly, humor. (O'Callaghan et al., 2013) Parents also commented on how the MMP served as a welcomed distractor at home for all family members, where conversations about making the child's movie provided 'something fun to think and talk about … instead of the other doom and gloom aspects of treatment and (Shrimpton et	"I think we had a good time working together. I think it was fun doing silly things. Sort of takes your mind off of it, but at the same time, gave you an opportunity to think about how you're dealing with it. We had a good time with the arts and crafts stuff. It was fun to just work together and dabble and play and be kids." (Brodeur, 2005) "It was something to look forward to, but the girls [siblings]I I'd be calling them and saying to them, Well, find some pictures,[and they'd start getting into it". (Mother; son, 13 years old) (Burns et al., 2010)	Brodeur, 2005, Burns et al., 2010, Jaser et al., 2014, Nicholas, O'Callaghan et al., 2013, Shrimpton et al., 2013, Wright et al., 2004

Theme: Improved Relationships		
	al., 2013) James’ mother said he was realizing, “There are things that go on that normal kids with no disabilities do that he can enjoy also. This helps him out the most. His brother and other kids can take karate, and so can he. (Wright et al., 2004)	

Theme: Improved Relationships			
Managing social situations /Targeting wider society	sense of isolation that often accompanies arthritis. Equally, raising awareness of the difficulties that may be experienced in social spheres combined with social skills training may assist children in negotiating their way through essential daily activities (e.g. attending school). (Barlow et al., 1999) The children are actively engaging with their treatment experience and using the BOC Program to visually tell others. All stories are meant to be told, and the BOC Program is afforded the participating children with a visual storytelling method. The BOC Program supports social protective outcomes (social integration and health care resources) for the child, as part of the resilience theory. (Baruch, 2012) the intervention group generally had a positive experience, reporting that the intervention was ‘‘helpful’’ or made them ‘‘feel better’’ in terms of both asthma symptoms and psychosocial functioning (Bignall et al., 2015) and developed coping skills for social interactions outside of camp. (Desai et al., 2014) A specific life skill many campers mentioned as an outcome of their participation at camp was the ability to manage their anger and to resolve conflicts with others. (Gillard et al., 2011) To ensure equitable access to social	A Junior Counselor shared that: “I was super nervous and shy ‘cause I was bald - being a girl and bald, it does not work that well! But [my mother] made me come and it was the best thing that could have ever happened to me. After I left camp, I wasn't shy.” (Gillard et al., 2013)	Barlow et al., 1999, Barnetz et al., 2012, Baruch, 2012, Bignall et al., 2015, Desai et al., 2014, Gillard et al., 2011/13, Hosek et al., 2012, Marsac et al., 2012, O’Callaghan et al., 2013; Shrimpton et al., 2013, Sibinga et al., 2011, Stewart et al., 2011b/13, Wright et al., 2004

Theme: Improved Relationships		
	networks after camp, camp administrators could provide formal and informal opportunities for further relationship building and nurturing for campers. Doing so would provide further contact between the positive social context of camp and individuals, as well as provide opportunities to teach others about HIV/AIDS through advocacy and educational efforts. This would also influence the development of a sense of belonging to a larger, supportive community. (Gillard et al., 2011) Campers and staff frequently mentioned in interviews social skill outcomes related to sociability, which were also observed in the field. All but two staff members cited specific examples of campers they knew who came to camp quiet and shy, but left camp laughing and hugging others. (Gillard et al., 2013) The participants also reported that interventions developed for young women living with HIV should devote time to disclosure. Specifically, teaching young women ‘‘how to disclose and who to tell’’ by improving communication and learning to evaluate the risks and benefits of disclosure to others. (Hosek et al., 2012) Secondary prevention interventions for young HIV-positive women should foster meaning, confidence, character, connection, and competence at the individual, relational, and collective levels	

Theme: Improved Relationships		
	in order to make lasting impact.40–44 If (Hosek et al., 2012) In study 1 (Cellie Kit comments), children reported that they would use the Cellie Kit for emotional expression, to practice techniques for talking to others about cancer, as a toy for fun, for comfort, and for distraction during procedures. (Marsac et al., 2012) Reconnecting with people after treatment may be eased when one can describe and musically illustrate their involvement in “normal,” interesting activities, alongside their illness experiences. (O’Callaghan et al., 2013) Explaining radiotherapy experiences to school peers and teachers “Lisa was facing some bullying so she showed the DVD to her class to help them comprehend what was going on … that they could still play with her and there was no need to be calling her names because her hair was falling out. So as far as coping and being accepted at school I think it helped a lot.” (Shrimpton et al., 2013) These effects appeared to have implications in terms of participants’ interpersonal relationships, school achievement, and physical health. (Sibinga et al., 2011) With regard to interpersonal relationships, most participants reported being able to get along better with family and friends by being more aware of their	

	Theme: Improved Relationships	
	stress and in turn reducing their reactivity and hostility toward others. (Sibinga et al., 2011) mentioned as an important concern upon probing this issue. The MBSR methods seem to have a positive effect in terms of ameliorating HIV-specific stressors such as taking medicines, fearing illness and death, experiencing stigma and discrimination, and disclosing HIV status. (Sibinga et al., 2011) Fifteen adolescents reported enhanced pre-existing friendships as they “figure(ed) out who my true friends were,” and “gave me some different things to discuss with my friends.”(Stewart et al., 2011b) Most children believed that they learned new techniques to handle social situations with peers, coaches, teachers, and parents. (Stewart et al., 2013a) For the younger participants and those with higher cognitive impairments, the development of appropriate social skills was frequently noted. Ms. Munday noted that the program gave Brandon the opportunity to work on age-appropriate skills such as taking turns and waiting. She stated, “Karate class gives him a good sense of limits.” Ms. Richards thought the program was good for Omar socially. She said, “I think he’s gotten better at listening, raising his hand when he wants to talk, focus more and follow what [the instructor] has to say. He’s very conscious	

	Theme: Improved Relationships	
	of the other kids and what they are doing." She noticed that he became less impulsive and did not interrupt others as frequently. His mother echoed these comments, saying, "His teachers always complain about him having a hard time waiting. All teachers describe how he fusses about waiting, but he is waiting here for karate." (Wright et al., 2004)	

Theme: Improved Relationships			
Improved relationships with healthy peers	However, it is apparent from the study that, despite the special quality of their relationships with other patients, these children also wanted to develop and maintain relationships with healthy peers. Smith et al. (1987) found that the oncology camp experience helped children form better relationships with healthy peers. (Bluebond-Langer et al., 1991) & Video used to talk with friends and family about AYA's experience (Burns et al., 2010) Power of the intervention to enhance connectedness among AYA, healthcare providers, family, and friends, centered on how the intervention fostered important relationships between AYA and others who could provide support and help. Many reported positive changes in AYA ability to communicate "previously unspoken thoughts" and renewed interest in social connections. (Docherty et al., 2013) Parents believed that the positive exchanges between the children and mentors helped children to form bonds with their peers and promote social cohesion. (Stewart et al., 2013a) Maintaining social connections with friends. (Shrimpton et al., 2013) Most children believed that they learned new techniques to handle social situations with peers, coaches, teachers, and parents. (Stewart et al., 2013a)	A 71-year old father stated his son "is more outspoken because, before, he wouldn't talk about things. And we had to explain to him, you know, you have to take your pills. Now he understands more by talking to other people." (Fair et al., 2012) "I think he felt better about missing out on the normal stuff, because he was able to tell and show them why. And they didn't make him feel like he missed out on anything, it was more like 'wow, look what Mark's been doing'. It helped him feel that six weeks out of his life hadn't made him an outcast. (Shrimpton et al., 2013) Fifteen adolescents reported enhanced pre-existing friendships as they "figure(ed) out who my true friends were," and "gave me some different things to discuss with my friends." (Stewart et al., 2011b)	Bluebond-Langer et al., 1991, Burns et al., 2010, Docherty et al., 2013, Fair et al., 2012, Shrimpton et al., 2013, Stewart, 2011; Stewart, 2013

Theme: Improved Relationships			
Improved support seeking/Relationships healthcare providers	Connectedness with the music therapist & Emotional connectedness with family & Connectedness with health care providers. (Baruch, 2012) From parents' perspective, the TMV intervention fostered connectedness with family members, the music therapist, other health care providers, and the music itself. (Burns et al., 2010) Power of the intervention to enhance connectedness among AYA, healthcare providers, family, and friends, centered on how the intervention fostered important relationships between AYA and others who could provide support and help. Parents repeatedly reflected on the synergistic benefits experienced by family when the intervention helped their AYA with relationships. Subthemes (Table 3) included: how the intervention enhanced AYA connectedness with health care providers, parents, and family members; (Docherty et al., 2013) Integrating the Cellie Kit into standard of care has the potential to help medical teams encourage communication between children, parents, and providers. For example, providers can use Cellie when talking to the child, can direct families to specific cards/pages in the book when they identify a challenge for their patients, or add their own tips to the cards/book that relate directly to the patient. Patients can also use the cards to	"We realize there are people out there, you just have to ask. A lot of times, people want to help, they just don't know how to offer their help." Participant #7 - 111 Woman - Follow-Up Interview, pg. 5 (Brodeur, 2005) "A parent stated, "(through the online network the ill child) has gotten to know (a health care provider) a lot better so he feels much freer, ...to go ask her for help." (Nicholas et al., 2007)	Brodeur, 2005, Baruch, 2012, Burns et al., 2010, Docherty et al., 2013, Marsac et al., 2012, Nicholas, 2007; Stewart, 2011/13; Wolf-Bordonaro, 2003,

Theme: Improved Relationships		
	communicate questions or concerns to their providers. (Marsac et al., 2012) Several participants felt that the level and quality of communication among the child, family and health care professionals had been favorably affected by network involvement. (Nicholas et al., 2007) Three teens thought increased confidence made it easier to “reach out” to able-bodied peers. (Stewart et al., 2011b) They became more comfortable to talk about their asthma and allergies and seek assistance from others. Most children believed that they learned new techniques to handle social situations with peers, coaches, teachers, and parents. they could seek support from their peers and the public. Indeed they became more confident in seeking support...they could seek support from their peers and the public. Indeed they became more confident in seeking support. (Stewart et al., 2013a) The researcher had an interesting opportunity to observe the assimilation of new information by one of the subjects. As reported in the Appendix K, the researcher escorted Subject 1 to her room following the Elimi-Pain Game. Upon reaching her room, Subject 1 stated she felt dizzy and required help to get into bed. The art therapist asked if she had eaten that day. Subject 1 explained that	

Theme: Improved Relationships		
	she didn’t eat breakfast, nor did she like the lunch that was served, so she had only eaten potato chips. Recalling a game card from the Elimi-Pain game, Letecia recalled that to stay healthy, she should eat nutritious foods. With that recollection she asked the art therapist if she would find something good for her to eat. (Wolf-Bordonaro, 2003)	

Theme: Improved Relationships			
Parents providing emotional support	Parents also reported learning about common reactions and experiences among families facing pediatric cancer and ways to promote communication about cancer within the family. (Marsac et al., 2012)	“(The Cellie Kit) helped him formulate questions so (that I could) understand exactly what he was looking for.” Similarly, one parent commented, “(The Cellie Kit) made us more comfortable talking about (cancer) with him. (Before receiving the Cellie Kit), there were a lot of things we probably wouldn't talk about.” (Marsac et al., 2012)	Marsac et al., 2012
Endured past endpoint	Impact of Living Well on family communication. Participants also noted that their families seemed to talk more, and subsequently understand each other better after participating in the program. Other participants noted that the program had an impact on their level of comfort in regards to sharing with others how they were feeling. ...Impact of Program on Family Dynamics Participants discussed how they felt the program had impacted their families in numerous ways, which have been classified into three sub-themes. Impact of Living Well on family cohesion. Several participants talked about how they felt the program had brought their family closer together. (Brodeur, 2005) A specific life skill many campers mentioned as an outcome of their participation at camp was the ability to		Brodeur, 2005, Gillard et al., 2011,

Theme: Improved Relationships	
	manage their anger and to resolve conflicts with others. (Gillard et al., 2011)

Theme: Hope and Inspiration				
Idea for further interpretation/ Third Order Construct	Second Order Construct	Quote	Papers contributing	Acknowledgement of overlap
Hope and Inspiration	The powerful influence of peers could be used positively by featuring adolescent characters in written materials and the use of peer leaders to deliver group education. (Barlow et al., 1999) The mentees reported on a relationship in which the principal and prominent element is a feeling of admiration for their mentors, enthusiasm about spending time together, about their lifestyle, and their ability to make diabetes part of their life....Numerous mentees reported that this admiration led them to adopt and emulate parts of their mentors' behavior regarding diabetes: If he does it and it seems so good, then maybe I can too. (Barnetz et al., 2012) Moreover, the children indicated that their healthy friends did not provide the hope, support, and encouragement that their friends with cancer provided: (Bluebond-Langer et al., 1991) Some talked about how meeting people who had gone through a similar experience and come through it had provided them with	"I think what they should have done is show the same child on a bad day and show them what they could be like on a good day so they will see the bad part and then they will know perhaps there's a light at the end of the tunnel." (Barlow et al., 1999) "It was fun like it's never been before, I saw someone who is in control of the situation and isn't afraid of diabetes. If he can do it, I've got to succeed....I'm less afraid because of the project; I met people there with amazing abilities." (Barnetz et al., 2012) "Since I might have to have a transplant, it's good to see someone who made it through one." (16-year-old male) (Bluebond-Langer et al., 1991) Seven children talked about the realization of these life possibilities. When asked about what a particular picture said about the camp, another said ''you can be anything that you want to be and that even though we have heart problems, we can still have an awesome time.''	Barlow et al., 1999, Barnetz et al., 2012, Bluebond-Langer et al., 1991, Brodeur, 2005, Bultas et al., 2015, Burns et al., 2010, Campbell et al., 2010, Fair et al., 2012, Gillard et al., 2011/13/16, Hosek et al., 2012, Kashikar-Zuck et al., 2016, Kirk et al., 2016, Lewis et al., 2016, Moola et al., 2015, Stewart et al., 2013a, White, 2014, Wright et al., 2004	

Theme: Hope and Inspiration		
	comfort and given them hope. (Brodeur, 2005) The last internal theme identified was called ‘‘life’s possibilities.’’ Many children with CHD understand the seriousness of their health condition, and this overnight experience helps them realize that there is life beyond medical treatments and hospitalization. The parents observed changes in behaviors and qualities of their AYAs through the TMV intervention. For example, their AYAs demonstrated enhanced self-esteem, discovered their inner strengths and beauty, and embraced life despite treatment-related changes to their outward appearance: (Burns et al., 2010) Participants had hope for the future even though some acknowledged that there might be difficulties especially in regard to disclosure of HIV status to romantic/sexual partners... A balance of recognising that there will be challenges to face in life ahead and the ability to remain optimistic and hopeful seems to characterise many of the responses reported here. Indeed, the title of this study was inspired	(Bultas et al., 2015) “The AYAs had a sense of purpose to the day, and hope: It was a project that we all focused on; it gave us all something to contribute to, and it’s a wonderful remembrance.” (Mother; son, 13 years old) (Burns et al., 2010) ‘‘I look forward. I feel insecure but I am OK with it’’ (Philip, 14 (Campbell et al., 2010) Another mother agreed: “more than anything else, being able to be around someone as themselves and see someone just like them and see that they’re doing things and going on with their lives and not having pity parties. I thought it was good.” (Fair et al., 2012) “Camp has really affected my life in many ways. I mean, I think the number one way it's affected my life is now I've learned about a bunch of people who have gone through what I've gone through and that they can continue living their life like a normal human being without having to think about all they've been through. And it makes you realize what everyone else is going through and that your life isn't so bad.”

Theme: Hope and Inspiration			
	by this quote: (Campbell et al., 2010) Being open and not having secrets provided hope and fun (Campbell et al., 2010) Positive changes in the adolescent were attributed to the experience of meeting other young people living with HIV. (Fair et al., 2012) Campers were often inspired to disclose their status through exposure to older or experienced campers, who freely shared information and stories about disclosure. Still, other campers refused to tell people their status for fear of damaging reactions. Throughout Camp Strong, self-presentation and social support contributed to the campers' constructed discourse of retaining hope through the struggle of living with HIV/AIDS (Gillard et al., 2011) Additionally, many campers expressed feelings of hope and encouragement because they were exposed to older youth and counselors who were long-term survivors For youth with cancer, hearing others' longevity and future-orientations suggested that they too could persevere and live a healthy life. (Gillard et al., 2013)	(Gillard et al., 2016) "Ask them who their role models are. They could be somebody famous or something like that. Be like, you see how they work hard to get that, you want to do that for yourself. You want that life for yourself." (Hosek et al., 2012) "I was thinking that if she can do it then I can do it too." (Kashikar-Zuck et al., 2016) "but encouraged others to persevere by highlighting the potential for this to be have future positive benefits. I know its horrible, but they're not going to take it out just because you don't use it, so do the feeds, show that you can eat enough to replace a few feeds so that your Doc will reduce the amount you need, and before you know it, they'll be saying 'OK, try not using it for a few months, and if you gain weight on your own, you can have it out" (Young person DG) (Kirk et al., 2016) "They (teachers, friends, and parents) are afraid – they think something is going to happen to me. I can't really do the things at home that I can do at camp. It made me want to get out there and it makes me feel like 'I can do	

Theme: Hope and Inspiration			
	A camper identified this theme of personal growth as the main take away from camp., (Gillard et al., 2016) Identifying and choosing positive role models were reported as necessary steps for young women to become empowered and to dream of a better life for themselves. The participants tended to discuss entertainment related role models as important for career success. However, young women also discussed the need positive role models living with HIV. Ask them who their role models are. They could be somebody famous or something like that. Be like, you see how they work hard to get that, you want to do that for yourself. You want that life for yourself. (Baltimore) (Hosek et al., 2012) Also, a natural tendency to cheer and support the other members or make suggestions about how to improve technique emerged within the group members which would not occur in a one-on-one training environment. (Kashikar-Zuck et al., 2016) Rather group norms appeared to be directed at maintaining a	this, even though I had surgery. I can still do things'– so it made me feel like I could still do the things I could do before. It (camp) would inspire other kids, it shows them that, that they can do more than they think they can. It will inspire them to do other things. (Moola et al., 2015) "So I think it will be great to see all different kinds of situations – there's some kids that have had a lot more surgeries than her. I think it's going to be really good for her to see that there's a whole variety of people with different heart conditions and then that they're living normally and having a good life too." (White14) And although Gary struggled with basic social skills, his mother also noted the salience of working with peers: "I like that he is in a class with other kids who have motor problems and that there is a range of disabilities—some kids are worse and some are better, but it's all okay. He tried a mainstream karate class and it didn't work out. Being in a karate class with his peers allows him to see what other kids with disabilities can do and be	

Theme: Hope and Inspiration		
	positive outlook, developing a sense of hope and discussing the day-to-day impact of illness on the young person/parent. (Kirk et al., 2016) Parents and ChIPS co-ordinators also spoke of observing the young people's strength of character and the capacity for ChIPS to engender a buoyant, positive attitude that flowed into daily life. (Lewis et al., 2016) She suggests that enhanced bodily freedom for cardiac children may inspire other patients to realise that they can succeed too. (Moola et al., 2015) The importance of peer support (especially peers who have diabetes) has also been demonstrated by other studies (Schur et al., 1999; Waller et al., 2005), with one specifically identifying peer role models with good control as a motivating influence (Kay et al., 2009). (Serlachius et al., 2012) Parents believed that their children were inspired to be like other children and their peer mentor. Participants learned that other children had more positive experiences and believed that if	comfortable in class." (Wright et al., 2004)

Theme: Hope and Inspiration		
	they emulated similar behavior, they would also be able to successfully manage their environments. They recognized that other children faced similar challenges and were able to cope. and were impressed that their children valued mentors as credible sources of support and positive role models. (Stewart et al., 2013a) Second, these camp interactions would allow the participants' children to understand and observe what other children with CHD can accomplish, and acknowledge that their own condition is not restricting. Third, caregivers perceived that camp would be an opportunity for their children to encourage one another and improve their own confidence. Four caregivers identified that their children would either encourage others to participate in activities, or be inspired by others if they were nervous and/or reluctant to engage in an activity (White, 2014)	

Theme: Hope and Inspiration				
Interventions which aren't peer support but also provide hope inspiration	Program to be a positive program that was a source of joy and encouragement. Five out of 10 clinicians spoke in the focus group about how the BOC Program provides “something positive to focus on,” (Baruch, 2012) Cognitive optimism regarding needle insertion enabled then to, in their words, "get through it." Positive statements such as "this taking part in the therapy trial offered hope. (Dennison et al., 2010) won't be so bad, she'll get it in on the first try," or "going through this will make me better," bespeak an optimism similar to what Irwin and Millstein refer to as optimistic bias. That is, an internalized belief that in the long term, the desired outcome of remission or cure will be achieved. (Weekes et al., 1993) Cognizant of the connection between hope and locus of control in children undergoing treatment for life threatening illness, the authors concluded that for the pediatric patients they studied, hope was “very important to the process of dealing with illness” (p. 407). They examined the link between hope and control, and proposed that whether young		Baruch, 2012, Dennison et al., 2010, O’Callaghan et al., 2012, Weekes et al., 1993, Wolf-Bordonaro, 2003	

Theme: Hope and Inspiration

	patients with chronic illness believed their disease was controlled by their physicians, parents, themselves, or all of these, was not as important as believing that it was controllable. The issue of hopefulness and decreased helplessness is very important to pediatric cancer patients. This is a primary issue…It may not matter so much whether a control is internal or external but whether the child believes that the disease can be controlled…Hope can come from believing that either the patient and/or powerful others are in control of the illness. (p. 53 (Wolf-Bordonaro, 2003) All stakeholders found the BOC			

Theme: More Than Just My Illness

Idea for further interpretation/ Third Order	Second Order Construct	Quote	Papers contributing	Acknowledgement of overlap

Construct			
Focusing on areas other than LTC valued by CYP	…or may have been concerned that attendance placed undue emphasis on HIV status rather than living a more ‘‘normal’’ life. (Campbell et al., 2010) At camp, there was no need to “shape shift,” or to align one’s presentation of self to match the context. Instead, campers more holistically integrated their identities at camp (Gillard et al., 2011) Further, youth with sickle cell typically receive little or no professional counseling or education (Acharya, Lang,&Ross, 2009), nordo they receive any from their communities because of stigma. Yet, at camp, youth could focus on other parts of their identities without the fear of negative appraisals.(Gillard et al., 2016) Need for comprehensive content. When asked what young HIV-positive women need to make healthier life choices and decrease risky behaviors, participants emphasized the need for comprehensive programs that extended beyond HIV specific topics. They requested programs that address a wide range of issues impacting their lives such as self-esteem, self-confidence, self-worth, living with HIV, sexuality, coping mechanisms, handling adversity, and developing and maintaining healthy relationships. (Hosek et al., 2012)	A camper focus group participant said, “They don't look at you like you're a cancer patient; they look at you like you're a person. They don't give you that pity.” (Gillard et al., 2013) “The body questions really make me aware of how much my body is affected by stress” (Whittemore et al. 2010)	Campbell et al., 2010, Gillard et al., 2011/13/16, Hosek et al., 2012, Muskat et al., 2016, O’Callaghan, Reme et al., 2013, Serlachius et al., 2012, Shrimpton et al., 2013, Stewart et al., 2013a, Whittemore et al. 2010

Most participants also demonstrated understanding of how the coping skills and physical exercise portions of the intervention were complementary (combined treatment).(Kashikar-Zuck et al., 2016)

Inconvenient locations for groups have been found to be a barrier to group attendance in adults with HIV (Rogers & Mapp, 2011); therefore the "one-stop" location for medical and psychosocial services likely enhanced group satisfaction, attendance, and participation. Evaluation of the groups by attendees, and parental caregivers support the assertion that the groups offered at the hospital succeeded in offering education, support, normalization, and mutual aid, in a very convenient location. (Muskat et al., 2016)

Even when a music interaction looks "trivial," for example "nonsense" song writing, there is considerable therapeutic benefit when children love to create and feel a sense of mastery: these actions signify resilience and continuation of their healthy self...The child's perception of their environment seems to alter from one that is tense to one that is friendly and engaging, possibly because their non-illness identity is being acknowledged Music therapy focuses on the "whole child" and their "wellness."

(O'Callaghan, 13)
Particular parts of the theory they found helpful were the association between thoughts, emotions, and body, and how negative thoughts and emotions can affect the body directly. This bears a high resemblance to CBT with only slight differences in terminology; where CBT would talk about challenging and changing unhelpful thoughts and beliefs, the Lightning Process would say something more like the following:
(Reme et al., 2013)
few participants did also acknowledge that general problems should also be discussed in the programme: ‘Time management was good, not just necessarily for your diabetes, but homework and social sorta stuff’ (Girl, 14 years). (Serlachius et al., 2012)
Furthermore, interviewees said that the positive portrayal of their son or daughter had allowed friends and family to see the child was ‘more than a sick kid’ and instead ‘a normal person who was being strong in a difficult situation’. This in turn generated expressions of admiration that left parents feeling ‘genuinely understood’ and the paediatric patient ‘brave and special’.
(Shrimpton et al., 2013)
focusing holistically on children’s lives rather than the chronic condition only.
(Stewart et al., 2013a)

Area of unmet need	A dominant theme across all focus groups concerned the failure of current psycho-educational interventions to address the wider aspects of JCA (e.g. psychosocial impact)...Parents believed that health professionals focused their attention on ‘disease activity’ rather than the child as a person or themselves as parents. (Barlow et al., 1999) The young people also appeared to hope for benefits from the therapy other than symptom resolution...a common theme was that the therapy was somehow incomplete and failed to tackle all aspects of the illness. ‘Psychological’ and emotional aspects appeared to be one area perceived to be ineffectively addressed (Dennison et al., 2010) Postings on the young people’s DG related to their sense of frustration that health-care professionals appeared unsupportive of their desire to participate in ‘normal’ teenage activities and thus support the development of a ‘normal’ identity. (Kirk et al., 2016) Interventions do not address the psychosocial aspects of coping with asthma in daily lives...While adolescents with asthma want support from nurses and other health professionals and from their peers, interventions continue to focus on disease-based education and management (Stewart et al., 2013a)	“They really don’t understand the problems you have at home... The doctors see them for half-an-hour...and examine the joints...but, it doesn’t just affect their joints. It affects them mentally and that’s what we have to put up with... “ (Barlow et al., 1999)	Barlow et al., 1999, Dennison et al., 2010, Kirk et al., 2016, Stewart et al., 2013a

Holistic interventions: as seen by CYP/ interventionists /authors	produced a sense of a more personalised treatment process whereby the child, rather than their illness, was recognised, made to feel special and cared for. (Shrimpton et al., 2013) or may have been concerned that attendance placed undue emphasis on HIV status rather than living a more ‘‘normal’’ life. (Campbell et al., 2010) At camp, there was no need to “shape shift,” or to align one’s presentation of self to match the context. Instead, campers more holistically integrated their identities at camp (Gillard et al., 2011) Further, youth with sickle cell typically receive little or no professional counseling or education (Acharya, Lang,&Ross, 2009), nor do they receive any from their communities because of stigma. Yet, at camp, youth could focus on other parts of their identities without the fear of negative appraisals. (Gillard et al., 2016) Need for comprehensive content. When asked what young HIV-positive women need to make healthier life choices and decrease risky behaviors, participants emphasized the need for comprehensive programs that extended beyond HIV specific topics. They requested programs that address a wide range of issues impacting their lives such as self-esteem, self-confidence, self-worth, living with	Camp staff aimed to provide for all of the campers' needs. A Junior Counselor explained, “Your physical needs are taken care of, your fun is taken care of.” A staff member focus group participant explains the camp's philosophy about supporting youths' physical activity: The hospital takes care of the physical and the medical needs, but the emotional and psychological needs, which are a lot of time ignored in the hospital, need to be met in a different arena and I think that's what [camp] provides in the activities in the fact that they can do them, they can all participate in them, they don't have to be left out or limited, makes them feel that good. (Gillard, 13) FIT Teens) almost doesn't make sense if they are separate...sometimes doing the more mental thing helps me more than going out and walking a mile...it gives you different ways to go at it. (Kashikar-Zuck et al., 2016)	Barnetz et al., 2012, Burns et al., 2010, Campbell et al., 2010, Gillard et al., 2011/13/16, Hosek et al., 2012, Kashikar-Zuck et al., 2016, Muskat et al., 2016, O’Callaghan et al., 2013, Reme et al., 2013, Serlachius et al., 2012, Shrimpton et al., 2013, Stewart et al., 2013a

HIV, sexuality, coping mechanisms, handling adversity, and developing and maintaining healthy relationships. (Hosek et al., 2012)

Most participants also demonstrated understanding of how the coping skills and physical exercise portions of the intervention were complementary (combined treatment).(Kashikar-Zuck et al., 2016)

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Evaluation of the groups by attendees, and parental caregivers support the assertion that the groups offered at the hospital succeeded in offering education, support, normalization, and mutual aid, in a very convenient location. (Muskat et al., 2016)

Even when a music interaction looks “trivial,” for example “nonsense” song writing, there is considerable therapeutic benefit when children love to create and feel a sense of mastery: these actions signify resilience and continuation of their healthy self...The child’s perception of their environment seems to alter from one that is tense to one that is friendly and engaging,

possibly because their non-illness identity is being acknowledged Music therapy focuses on the “whole child” and their “wellness.”
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(Reme et al., 2013)

few participants did also acknowledge that general problems should also be discussed in the programme: ‘Time management was good, not just necessarily for your diabetes, but homework and social sorta stuff’ (Girl, 14 years). (Serlachius et al., 2012)

Furthermore, interviewees said that the positive portrayal of their son or daughter had allowed friends and family to see the child was ‘more than a sick kid’ and instead ‘a normal person who was being strong in a difficult situation’. This in turn generated expressions of admiration that left parents feeling ‘genuinely understood’ and the paediatric patient ‘brave and special’.
(Shrimpton et al., 2013)

	focusing holistically on children's lives rather than the chronic condition only. (Stewart et al., 2013a)"The body questions really make me aware of how much my body is affected by stress"; (Whittemore et al. 2010) Acknowledgement by studies that holistic care important	

Focus holistically on child lives/whole child: role of services/intervention. Unmet need.	Parents' and children's thirst for knowledge appeared to be unquenchable. They wanted to know more about disease management in the home environment, the psychosocial impact of JCA and their children's future prospects.(Barlow et al., 1999) According to Keller and Pryce (2010), a recreational partner relationship places greater emphasis on an adolescent-oriented approach (enjoyment and interest) than on an adult-oriented approach (structure, contribution, and development). As noted in the review of the literature, they contend that placing excessive emphasis on one at the expense of the other is likely to be problematic....On many occasions when professionals encounter such adolescents, who actually ignore numerous aspects of their disease, they attempt to provide them with knowledge on the implications of their actions, but the threatening knowledge might have the opposite effect: it will only increase the anxiety that caused the adolescent to ignore the disease in the first place. This line of thinking echoes the conclusion of Hood et al. (2010) whereby focusing on juvenile diabetic adherence behavior and neglecting emotional and social factors is unlikely to have a positive impact....The second possibility is a situation wherein the disease actually	"Finally there's someone I can share things with, not somebody who says 'do this' or 'do that', but somebody who understands that life is more than the medical aspect." (Barnetz et al., 2012) "It got us only so far, it was slightly limited. It was a little bit narrow in that it focused on one thing, but didn't look at all the other factors" (P 5 2 CBT). (Dennison et al., 2010) A Junior Counselor explained, "Your physical needs are taken care of, your fun is taken care of." A staff member focus group participant explains the camp's philosophy about supporting youths' physical activity: The hospital takes care of the physical and the medical needs, but the emotional and psychological needs, which are a lot of time ignored in the hospital, need to be met in a different arena and I think that's what [camp] provides in the activities in the fact that they can do them, they can all participate in them, they don't have to be left out or limited, makes them feel that good." (Gillard et al., 2013) "My perfect program wouldn't	Barlow et al., 1999, Barnetz et al., 2012, Burns et al., 2010, Campbell et al., 2010, Dennison et al., 2010, Gillard et al., 2016/11/13, Hosek et al., 2012, Kashikar-Zuck et al., 2016 , Kirk et al., 2016, O'Callaghan et al., 2013, Muskat et al., 2016, Reme et al., 2013, Serlachius et al., 2012, Shrimpton et al., 2013, Stewart et al., 2013a, Whittemore et al. 2010,	A new normal

	controls the adolescents’ life: when an adolescent and his or her family valiantly join forces in order to maintain a lifestyle that will ensure maximal health, but along the way they ‘forget’ the importance of quality of life in the present. In cases such as this we see a Adolescent Perception of Mentor–Mentee Relationships 479 ‘grave-faced’ coping with the disease, the blood tests, blood sugar balance, and proper behavior, all of which threaten to deplete the child as well as the family of energy and joie de vivre. It seems that one of the present study’s principal messages for us, the professionals, is that in order to help these adolescents live their life in a way in which their medical condition is enhanced, we must constantly bear in mind that ‘‘life with diabetes is more than the medical aspect’’ (Barnetz et al., 2012) & Offers holistic care (Burns et al., 2010) or may have been concerned that attendance placed undue emphasis on HIV status rather than living a more ‘‘normal’’ life. (Campbell et al., 2010) The young people also appeared to hope for benefits from the therapy other than symptom resolution...a common theme was that the therapy was somehow incomplete and failed to tackle all aspects of the illness. ‘Psychological’ and emotional aspects appeared to be one	just not only be focused on the infection. It would just really be building self-worth, building self-esteem like all the way around. So many youth have a hard time just making that transition perhaps to the college, and still be like do they have to take care of themselves, either by nutrition, I mean, like my program, it was just, I couldn’t, I could just say it. I would do it.” (Hosek et al., 2012) “(FIT Teens) almost doesn't make sense if they are separate...sometimes doing the more mental thing helps me more than going out and walking a mile...it gives you different ways to go at it.” (Kashikar-Zuck et al., 2016) “It seems like they say that you shouldn’t let CF control you, then they insist upon CF being an absolute priority- over Parties and other great things. [...] what is the point of all this healthcare if you aren’t using it to ‘earn’ a step closer to normality they need to learn to let you have a balance between health and life” (Kirk et al., 2016) “The body questions really make	

	area perceived to be ineffectively addressed (Dennison et al., 2010) At camp, there was no need to “shape shift,” or to align one’s presentation of self to match the context. Instead, campers more holistically integrated their identities at camp (Gillard et al., 2011) Camp staff aimed to provide for all of the campers' needs...As reported in this study, the camp contained features that supported developmental experiences, which is especially important because youth with cancer are especially at risk of negative outcomes such as anxiety, depression, and isolation Camp staff aimed to provide for all of the campers' needs...As reported in this study, the camp contained features that supported developmental experiences, which is especially important because youth with cancer are especially at risk of negative outcomes such as anxiety, depression, and isolation (Gillard et al., 2013) Campers with cancer perceived camp as a place for sense of belonging, personal growth, and escape. Campers with HIV/AIDS perceived camp as an opportunity for a sense of belonging, being myself, camp programming, and escape. Campers with sickle cell disease perceived camp as a place for enjoyment, adult staff, being myself, personal growth, and escape. Campers with metabolic diseases perceived camp	me aware of how much my body is affected by stress” (Whittemore et al. 2010)

as a place for personal growth and positive affect.(Gillard et al., 2016)

Need for comprehensive content. When asked what young HIV-positive women need to make healthier life choices and decrease risky behaviors, participants emphasized the need for comprehensive programs that extended beyond HIV specific topics. They requested programs that address a wide range of issues impacting their lives such as self-esteem, self-confidence, self-worth, living with HIV, sexuality, coping mechanisms, handling adversity, and developing and maintaining healthy relationships. (Hosek et al., 2012)

Most participants also demonstrated understanding of how the coping skills and physical exercise portions of the intervention were complementary (combined treatment).(Kashikar-Zuck et al., 2016)

Postings on the young people’s DG related to their sense of frustration that health-care professionals appeared unsupportive of their desire to participate in ‘normal’ teenage activities and thus support the development of a ‘normal’ identity. (Kirk et al., 2016)

Inconvenient locations for groups have been found to be a barrier to group attendance in adults with HIV (Rogers & Mapp, 2011); therefore the “one-stop” location for medical and psychosocial services likely enhanced group satisfaction, attendance, and participation. Evaluation of the groups by attendees, and parental caregivers support the assertion that the groups offered at the hospital succeeded in offering education, support, normalization, and mutual aid, in a very convenient location. (Muskat et al., 2016)

Even when a music interaction looks “trivial,” for example “nonsense” song writing, there is considerable therapeutic benefit when children love to create and feel a sense of mastery: these actions signify resilience and continuation of their healthy self...The child’s perception of their environment seems to alter from one that is tense to one that is friendly and engaging, possibly because their non-illness identity is being acknowledged. Music therapy focuses on the “whole child” and their “wellness.”
(O'Callaghan, 13)

Particular parts of the theory they found helpful were the association between thoughts, emotions, and body, and how negative thoughts and emotions can affect the body directly. This bears a high resemblance to CBT with only slight differences in terminology; where CBT would talk about challenging and changing unhelpful thoughts and beliefs, the Lightning Process would say something more like the following:

(Reme et al., 2013)

few participants did also acknowledge that general problems should also be discussed in the programme: ‘Time management was good, not just necessarily for your diabetes, but homework and social sorta stuff’ (Girl, 14 years). (Serlachius et al., 2012)

Furthermore, interviewees said that the positive portrayal of their son or daughter had allowed friends and family to see the child was ‘more than a sick kid’ and instead ‘a normal person who was being strong in a difficult situation’. This in turn generated expressions of admiration that left parents feeling ‘genuinely understood’ and the paediatric patient ‘brave and special’. (Shrimpton et al., 2013)

Interventions do not address the psychosocial aspects of coping with asthma in daily lives...While adolescents with asthma want support from nurses and other health professionals and from their peers, interventions continue to focus on disease-based education and management (Stewart et al., 2013a)

psychosocial/educational needs/self-expression/control	The voices of children and their parents were as one in expressing an overwhelming need for greater availability, easier access and more comprehensive psychoeducational interventions in the context of JCA….The parents and children in the present study felt that professionals (i.e. health, social services and education) failed to appreciate their needs, particularly in relation to the psychosocial impact of JCA.(Barlow et al., 1999) The second possibility is a situation wherein the disease actually controls the adolescents' life: when an adolescent and his or her family valiantly join forces in order to maintain a lifestyle that will ensure maximal health, but along the way they 'forget' the importance of quality of life in the present. In cases such as this we see a 'grave-faced' coping with the disease, the blood tests, blood sugar balance, and proper behavior, all of which threaten to deplete the child as well as the family of energy and joie de vivre. (Barnetz et al., 2012) the finding that some patients felt that therapy failed to address the emotional impact of CFS suggests that a different approach to managing emotions may be needed. (Dennison et al., 2010) Participants discussed their experiences of interacting with friends at night, practising for their talent show,	"Yeah, you have that [HIV] and at the same time you have to learn to support yourself. Then like as we talk about reject, you think like everybody gonna reject you and you think like, okay, this is the end of the world. I cannot do anything. You have to learn to help yourself, give self-esteem to yourself, and be YOU." (Hosek et al., 2012)	Barlow et al., 1999, Barnetz et al., 2012, Dennison et al., 2010, Desai et al., 2014, Gan et al., 2010, Gillard et al., 2011, Hosek et al., 2012, Kashikar-Zuck et al., 2016, Kirk et al., 2016, Nicholas et al., 2007, Reme et al., 2013, Serlachius et al., 2012, Stewart et al., 2013a, Whittemore et al. 2010, Wolf-Bordonaro, 2003	Skills/Knowledge

personalizing and decorating their space, and sleeping in bunk beds as important aspects of staying in cabins at the camp. (Desai et al., 2014)

The BIFI-A encompasses a broad curriculum, comprised of multiple components: education, emotional support and skill building. (Gan et al., 2010)

Need for comprehensive content. When asked what young HIV-positive women need to make healthier life choices and decrease risky behaviors, participants emphasized the need for comprehensive programs that extended beyond HIV specific topics. They requested programs that address a wide range of issues impacting their lives such as self-esteem, self-confidence, self-worth, living with HIV, sexuality, coping mechanisms, handling adversity, and developing and maintaining healthy relationships. (Hosek et al., 2012)

Most participants also demonstrated understanding of how the coping skills and physical exercise portions of the intervention were complementary (combined treatment). (Kashikar-Zuck et al., 2016)

A striking feature was the personalization of postings through the inclusion of photographs and signature lines providing information about family context (Kirk et al., 2016)

In summary, SBW was appreciated for

	its provision of education in terms of not only health information but also its non-illness content. For this reason, the network offered opportunities to learn about topics unrelated to health, thereby normalizing the children’s environment.(Nicholas et al., 2007) Particular parts of the theory they found helpful were the association between thoughts, emotions, and body, and how negative thoughts and emotions can affect the body directly. This bears a high resemblance to CBT with only slight differences in terminology; where CBT would talk about challenging and changing unhelpful thoughts and beliefs, the Lightning Process would say something more like the following: (Reme et al., 2013) coping strategies not only equip adolescents with the skills they need to manage the stressors of adolescence (Serlachius et al., 2012) Interventions do not address the psychosocial aspects of coping with asthma in daily lives...While adolescents with asthma want support from nurses and other health professionals and from their peers, interventions continue to focus on disease-based education and management (Stewart et al., 2013a) “The body questions really make me aware of how much my body is affected by stress”;(Whittemore et al. 2010)	

	The protocol for this study included three art therapy interventions. The interventions were designed to increase the internality of subjects’ LOC by familiarizing them with the hospital environment, providing opportunities for control and expression, and addressing established cognitive structures regarding their treatment and medical condition. (Wolf-Bordonaro, 2003)	

learn about selves e.g. strengths/weaknesses/hopes for future/identity (self-knowledge)	At camp, there was no need to “shape shift,” or to align one’s presentation of self to match the context. Instead, campers more holistically integrated their identities at camp...Because of camp connections, campers felt free of the need to “hide in the phone booth” and got to be “Superman,” their super selves. (Gillard et al., 2011) Further, youth with sickle cell typically receive little or no professional counseling or education (Acharya, Lang,&Ross, 2009), nor do they receive any from their communities because of stigma. Yet, at camp, youth could focus on other parts of their identities without the fear of negative appraisals.(Gillard et al., 2016) Children with disabilities in Goodwin and Staples’ (2005) study similarly suggested that camp provided them with the ‘chance to discover’ the limits of their physical potential, laying doubts about physical limitations to rest. (Moola et al., 2015) music can arguably be a safe haven and companion for grappling with internalizing a healthy self-image alongside patient identity, and this may occur nonverbally and pre-verbally. (O’Callaghan et al., 2013) For seven participants, self awareness was enhanced through social comparison. “It helped me understand a bit more about myself and my	“And so really the group became a way for them to help one another, and the older kids sort of took over in that regard, and kind of became peer counselors in a way and were able to help them answer some responses to people [.] there was one girl, the oldest girl in the class, just felt like everyone should be out and open about it and perhaps that would release the stigma. So really a means for them to figure things out on their own and figure out how they wanted to represent themselves and HIV or if they wanted that to be a part of who they were.” (Fair et al., 2012)	Fair et al., 2012, Gillard et al., 2016/11, Moola et al., 2015, O’Callaghan et al., 2013, Stewart et al., 2011b

limitations and my goals” (Stewart et al., 2011b)

Acknowledge wider systems e.g. family and social	Content of future psycho-educational interventions Essential disease-related information (e.g. aetiology, symptoms) Treatment-related information (e.g. medication, exercise, use of aids) Side-effects of treatment Time commitment needed Psychological and social impact Self-management strategies (e.g. relaxation, cognitive pain management) Assertiveness training for parents and children Communication skills for children, parents and health professionals Social skills training, particularly for children ...Moreover, camps were believed to recognized the fact that JCA affects all members of the family.(Barlow et al., 1999) Need for comprehensive content. When asked what young HIV-positive women need to make healthier life choices and decrease risky behaviors, participants emphasized the need for comprehensive programs that extended beyond HIV specific topics. They requested programs that address a wide range of issues impacting their lives such as self-esteem, self confidence, self-worth, living with HIV, sexuality, coping mechanisms, handling adversity, and developing and maintaining healthy relationships. ...If secondary prevention interventions fail to address the relationships these young women have, and the environment in which they live (i.e., community and society at large), the interventions may	“Mom was over-protective after my injury because she was worried about me [teen 5]. .. . that my mom and dad get stressed out too and I learned some things to try to calm down when I am frustrated” [CYP, ABI] (Gan et al., 2010 2010, p659) “I think that it will do me good to let her go. Letting her go for a week with people I don’t even know – I’ve never done that before. It will be good for us to know that she can go and she’s going to be fine.”[Parent, CHD] (White, 2014 p45)	Barlow et al., 1999, Gan et al., 2010, Hosek et al., 2012, Nicholas et al., 2007, O’Callaghan et al., 2013, Shrimpton et al., 2013, Stewart et al., 2013a, White, 2014

fall short of providing lasting and meaningful impact. (Hosek et al., 2012)

Cumulatively then, the network offered personal benefits of increased control and mastery as well as a variety of issues to discuss, a mutually rewarding environment for interaction, and a positive source of relationship-building. Participants described beneficial outcomes of greater communication as peer, family and health care provider dialogue was facilitate (Nicholas et al., 2007)

It may appear ironic that music's profound importance in children's adaptive living is grounded in music's capacity to enable connective relationships, alongside separation and identity (O'Callaghan et al., 2013)

Furthermore, interviewees said that the positive portrayal of their son or daughter had allowed friends and family to see the child was 'more than a sick kid' and instead 'a normal person who was being strong in a difficult situation'. This in turn generated expressions of admiration that left parents feeling 'genuinely understood' and the paediatric patient 'brave and special'. (Shrimpton et al., 2013)

Interventions do not address the psychosocial aspects of coping with asthma in daily lives...While adolescents with asthma want support from nurses and other health professionals and from

	their peers, interventions continue to focus on disease-based education and management (Stewart et al., 2013a)			

Theme: A New Normal

Idea for further interpretation/ Third Order	Second Order Construct	Quote	Papers contributing	Acknowledgement of overlap

Theme: A New Normal			
Construct			
Taking part in everyday activities	The foci of parents’ concerns were to ensure that their children had similar opportunities for self-development as children without JCA and to provide a sense of ‘normality’ in children’s lives. (Barlow et al., 1999) parents also felt it offered opportunity for the AYAs to exert control over the environment by making choices, creating something meaningful, and experiencing a sense of normalcy in the midst of an overwhelming focus on the illness and medical treatments: (Burns et al., 2010) That said, the theme that therapy was a principal factor in allowing patients to regain normality in lives was very common, especially within the CBT participants. ‘I’m absolutely sure the CBT was probably the most important contributory factor to the recovery’ (P 9 2 CBT). (Dennison et al., 2010) Throughout camp, several campers were observed being advised by counselors and other campers to relax, just have fun, and to be a kid. The developmental experiences related to “just being a kid” were discussed by interview and focus group participants as experiences that were not typically available to youth with cancer (Gillard et al., 2013)	“think he kind of took hold of what little piece of life he could, and it made him happy that he could do something instead of just sit there and have everything thrown at him and it made him more confident tooI helped boost him up.” (Mother; son, 13 years old) (Bultas et al., 2015) “I’m actually getting to live a life.” (Dennison et al., 2010) “I used activity pacing didn't push myself too far and I was still able to stay with my friends and do what they were doing.” (Kashikar-Zuck et al., 2016) mother indicated that the network offered an alternative to active play for her ill son. She described her son as, “a very active (child) . . . Because he can’t always go out and play, I think to be able to do it vicariously through the computer has been really good for him.” (Nicholas et al., 2007) James’ mother said he was realizing, “There are things that go on that normal kids with no disabilities do that he can enjoy also. This helps him out the most.	Barlow et al., 1999, Bultas et al., 2015, Burns et al., 2010, Dennison et al., 2010, Gillard et al., 2013/16, Kashikar-Zuck et al., 2016, Moola et al., 2015, Nicholas et al., 2007, Sibinga et al., 2011, White, 2014, Wolf-Bordonaro, 2003, Wright et al., 2004

Theme: A New Normal			
	and the developmental supports found in medical summer camp can help youth gain a sense of normalcy in personal and social experiences that is otherwise absent. (Gillard et al., 2016) During the program, all participants noted that they had increased their overall daily physical activity, incorporated planned physical activities into their daily schedules (Table 7), and experienced increased motivation to go out or be with their friends even if they had pain. (Kashikar Zuck) such as the importance of providing sick children with fun, independence, mastery experiences, friendship and a sense of normalisation in an outdoor environment (Moola et al., 2015) A health care provider commented that online network participation provided children with an opportunity to, “have fun in a normalized way, by playing on a computer, doing things they would do at home.” (Nicholas et al., 2007 Children who learn instruments before the diagnosis may continue to play in hospital, (O’Callaghan et al., 2013) School achievement Doing better in school appeared to be connected to reduced stress, increased concentration, and greater confidence. Several participants explicitly mentioned meditating or doing breathing exercises right before doing their homework or	His brother and other kids can take karate, and so can he.” (Wright et al., 2004)	

	Theme: A New Normal	
	taking a test in order to reduce their stress. Others discussed how being more ‘‘present’’ as a result of MBSR techniques helped them to concentrate on their work, rather than ‘‘zoning out.’’(Sibinga et al., 2011) Lastly, these caregivers anticipated that their children would be able to experience camp just like their typically developing peers as Julie describes, “it’ll allow her to actually go to camp and experience canoeing and all the things that every healthy kids gets to experience all the time – in a controlled environment too.” (White, 2014) engaged patients in normalizing activity, (Wolf-Bordonaro, 2003)	

Theme: A New Normal				
Link with normal life/Being embedded in normalcy	Recently, members of camp-planning committees have raised the fol. lowing question: Should camp be extended beyond the 7-to-14-day sessions presently offered? Given the children's desire to develop and maintain relationships with healthy peers, extending the camp session seems inappropriate, in fact, longer camp sessions, which would remove pedialric cancer patients from contact with healthy peers for longer periods (Bluebond-Langer et al., 1991) Through the TMV intervention, the AYAs became engaged and motivated in life, with family and the environment. (Bultas et al., 2015) parents also felt it offered opportunity for the AYAs to exert control over the environment by making choices, creating something meaningful, and experiencing a sense of normalcy in the midst of an overwhelming focus on the illness and medical treatments: (Burns et al., 2010) or may have been concerned that attendance placed undue emphasis on HIV status rather than living a more ‘‘normal’’ life. (Campbell et al., 2010) That said, the theme that therapy was a principal factor in allowing patients to regain normality in lives was very common, especially within the CBT participants. ‘I'm absolutely sure the CBT	Lastly, these caregivers anticipated that their children would be able to experience camp just like their typically developing peers as Julie describes, “it'll allow her to actually go to camp and experience canoeing and all the things that every healthy kids gets to experience all the time – in a controlled environment too.” (White, 2014)	Bluebond-Langer et al., 1991, Bultas et al., 2015 , Burns et al., 2010, Campbell et al., 2010, Dennison et al., 2010, Gillard et al., 2011, Kashikar-Zuck et al., 2016, Kirk et al., 2016, Muskat et al., 2016, Nicholas et al., 2007, O'Callaghan et al., 2013, Reme et al., 2013, Shrimpton et al., 2013, White, 2014,	Hope/Inspiration, Keeping it going, Accessibility, Resources/Availability , Adapting to interests of child/relevance. Link Kirk et al., 2016: idea of illness separating.

	Theme: A New Normal	
	was probably the most important contributory factor to the recovery’ (P 9 2 CBT).(Dennison et al., 2010) To ensure equitable access to social networks after camp, camp administrators could provide formal and informal opportunities for further relationship building and nurturing for campers. Doing so would provide further contact between the positive social context of camp and individuals, as well as provide opportunities to teach others about HIV/AIDS through advocacy and educational efforts. This would also influence the development of a sense of belonging to a larger, supportive community. (Gillard et al., 2011) During the program, all participants noted that they had increased their overall daily physical activity, incorporated planned physical activities into their daily schedules (Table 7), and experienced increased motivation to go out or be with their friends even if they had pain. (Kashikar-Zuck et al., 2016) Young people emphasized their ‘normal’ identify in postings, describing the normality of life with CF (Kirk et al., 2016) Evaluation of the groups by attendees, and parental caregivers support the assertion that the groups offered at the hospital succeeded in offering education, support, normalization, and mutual aid,	

<table>
<tr><th colspan="3">Theme: A New Normal</th></tr>
<tr><td></td><td>in a very convenient location. (Muskat et al., 2016)
In response, a mother advocated widespread availability of the network to children in hospital. She further recommended access within all patient rooms: (The ill child) would say to me, “oh Mom, look at that beautiful playroom and I can’t even go.” And at one point there was (another child) across the hall from her and they wanted to talk so bad, but they couldn’t because they both had different bugs ...If they had a computer, between them, they could have had a great time. So, I’m thinking down the road when computers are in every room, it will make kids’ lives a lot more normal. (Nicholas et al., 2007)
A therapist also recorded one patient’s performance for replay at a school concert when treatment prevented her attendance. (O’Callaghan et al., 2013)
Unlike other treatments where you can openly share your treatment experiences with other people, participants undergoing the Lightning Process are specifically encouraged not to talk to anyone about it. One ofthe participants describes it like this: ‘…and also because you are not really supposed to talk about it with other people, is what he said, because it only confuses you and them. You don’t have anyone to talk to about it with so you feel kind of alone’ (Reme et</td><td></td></tr>
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	Theme: A New Normal	
	al., 2013) Beyond these outcomes, Pippa’s mother also recalled how being able to involve her daughter’s twin sister in the movie’s production (an activity that allowed the two children to play and laugh together) gave the family a sense of normalcy and close involvement in Pippa’s treatment. (Shrimpton et al., 2013)	

Theme: A New Normal			
Acceptance of limitations/symptoms with link to hope	Parents suggested that the use of successful role models (i.e. young adults who had achieved their goals) in educational material would assist the process of adjustment and acceptance....This mentee met with a mentor who maintained his balance quite naturally while performing everyday activities such as computer games and listening to music. (Barnetz et al., 2012) They also expressed optimism for the future, although this was tempered with acknowledgement of challenges....Several participants noted that as a result of attending they accepted that medication was a part of their lives and something they had to cope with... Participants had hope for the future even though some acknowledged that there might be difficulties especially in regard to disclosure of HIV status to romantic/sexual partners. (Campbell et al., 2010) Nonetheless, all the young peoples' health had dramatically improved post-therapy. 'I'm actually getting to live a life. And the symptoms are more just part of that 2 now if I get them they just sort of run alongside and they are managed' (YP 4 2 CBT)...Interestingly, most participants appeared to find the extent of improvement acceptable. (Dennison et	"I feel happier and know that I am not alone and I am not afraid anymore. I feel less scared now. I feel not as worried about the future as I did before. I know that I am not the only one with it and that I can do most things that other people can do but just need to be careful. I know that I have somewhere to talk about things, although I can talk to my aunt, it is good to talk to people my age as well and be open about things. I feel better about managing and looking after myself in the future, but know that it will depend on the situation." (Campbell et al., 2010). "Today, I do embrace my disability and the fact that I have HIV"(Fair et al., 2012) "I guess it puts it more into perspective about how you might not necessarily have it the worst, like out of everyone. I guess appreciate – like I wouldn't say life – but you appreciate your situation a bit more. I think it (camp) was a good for me. I think especially because when I was first diagnosed and I couldn't play sports and that was grade nine. I was like really mad every day, I was so mad for like a whole year,	Barnetz et al., 2012, Campbell et al., 2010, Dennison et al., 2010, Docherty et al., 2013, Fair et al., 2012, Hosek et al., 2012, Kashikar-Zuck et al., 2016, Kirk et al., 2016, Moola et al., 2015, Stewart et al., 2013a, White, 2014

	Theme: A New Normal		
	al., 2010) increased acceptance, and thriving beyond surviving. (Docherty et al., 2013) Participants discussed the need for interventions that empowered young women not only through education, but by learning to support, accept and value themselves. (Hosek et al., 2012) During the program, all participants noted that they had increased their overall daily physical activity, incorporated planned physical activities into their daily schedules (Table 7), and experienced increased motivation to go out or be with their friends even if they had pain.(Kashikar-Zuck et al., 2016) Although the young people posted queries relating to the management of medications/therapies, their postings revealed more of a concern about how to live with CF (Kirk et al., 2016) All caregivers believed that if their children were put in a situation where they were not able to engage in an activity due to their cardiac limitations, their children would adapt Fair et al., 2012ly well. Since camp was perceived as a safe environment with staff sensitive to their needs, children would not feel uncomfortable and/or upset if they could not engage in a specific activity: (White, 2014)	yeah. It was a good to see like 'maybe sports isn't everything, it's not everything in the world' and some people, they can't even like run around with their friends. It's not necessarily the worst, thing that could happen. It put things into better perspective." (Moola et al., 2015) "She became a lot more comfortable with her asthma and issues that might be around it and more diligent about taking her medication." (Stewart et al., 2013a)	

Theme: A New Normal			
Sense of acceptance/no need for LTC to take over	The mentees' reports revealed several layers of learning, and a central mechanism through which this learning occurred. The first type of learning is of a basic attitude toward diabetes. This is not learning of a specific skill, but of the place of diabetes in the adolescents' life and the way they should perceive and contend with the disease. (Barnetz et al., 2012) The last internal theme identified was called ''life's possibilities.'' Many children with CHD understand the seriousness of their health condition, and this overnight experience helps them realize that there is life beyond medical treatments and hospitalizations. (Bultas et al., 2015) Increased acceptance, and thriving beyond surviving. (Dennison et al., 2010) Virtually all of the participants acknowledged that young women will inevitably continue to face disappointment, rejection and lack of support, but that an intervention could provide young women with the knowledge and skills they needed to better handle those situations when they arise. (Hosek et al., 2012) Although the young people posted queries relating to the management of medications/therapies, their postings revealed more of a concern about how to live with CF (Kirk et al., 2016) During the program, all participants	"When asked what he had learned, he replied, I learned what it is to be a diabetic, what being balanced is" (Barnetz et al., 2012) "I feel happier and know that I am not alone and I am not afraid anymore. I feel less scared now. I feel not as worried about the future as I did before. I know that I am not the only one with it and that I can do most things that other people can do but just need to be careful. I know that I have somewhere to talk about things, although I can talk to my aunt, it is good to talk to people my age as well and be open about things. I feel better about managing and looking after myself in the future, but know that it will depend on the situation." (Campbell et al., 2010) 'I'm actually getting to live a life. "And the symptoms are more just part of that 2 now if I get them they just sort of run alongside and they are managed' (YP 4 2 CBT)." (Dennison et al., 2010) "It can be up to you how. The first thing I can say, like I should say, realize what is it. Like when you know WHAT it is, then accept yourself first before you want	Barnetz et al., 2012, Bultas et al., 2015, Campbell et al., 2010, Dennison et al., 2010, Hosek et al., 2012, Kashikar-Zuck et al., 2016, Kirk et al., 2016, Muskat et al., 2016, White, 2014, Wright et al., 2004,

Theme: A New Normal			
	noted that they had increased their overall daily physical activity, incorporated planned physical activities into their daily schedules (Table 7), and experienced increased motivation to go out or be with their friends even if they had pain. (Kashikar-Zuck et al., 2016) Participants shared advice on how to integrate complex treatment regimens into everyday life, (Kirk et al., 2016) Second, these camp interactions would allow the participants’ children to understand and observe what other children with CHD can accomplish, and acknowledge that their own condition is not restricting. (White, 2014)	other people to accept you. Then once you just tell yourself, okay, this is what I have, and this is me, and there’s nothing wrong about me. It’s just the HIV, and if you think HIV is living you, and living with it, so that’s another problem. You don’t have to just, so okay, I have HIV, I cannot go to school, I cannot do this, I cannot do that. You can still be a doctor while you’re HIV positive. You can still do everything. So that’s the thing, I mean, I think you have to accept yourself.” (Hosek et al., 2012) This program) helped me not just lay around when I was hurting. It helped me get up and do something even when I am hurting. Usually I'd be stuck inside the house and I didn't feel like going out and doing stuff... I'm hanging out with more friends...exercising and taking walks (Kashikar-Zuck et al., 2016) One parental caregiver commented, “He’s learned you can have a normal life with the group because of the things they teach them, he has learned safety, HIV protection against people, they teach everything,	

Theme: A New Normal
they really do.” (Muskat et al., 2016)

Theme: A New Normal				
Acceptance of death	Parents thought the TMV intervention benefited their AYAs as a holistic and creative way to derive meaning by working through their existential plight. For example, the intervention was perceived as a nonthreatening means to discuss death and a form of life review: (Burns et al., 2010) Particularly important are parent statements that the intervention helped AYA face their illness and in some cases their mortality. (Docherty et al., 2013)		Burns et al., 2010 Docherty et al., 2013	Contradicts avoidance of death: Boundaries

Theme: A New Normal			
Comparing to peers/coping/positive perspectives	The mentees' reports revealed several layers of learning, and a central mechanism through which this learning occurred. The first type of learning is of a basic attitude toward diabetes. This is not learning of a specific skill, but of the place of diabetes in the adolescents' life and the way they should perceive and contend with the disease. (Barnetz et al., 2012) Of the same clinicians surveyed, words to describe the BOC Program included in their survey responses included: "positive spin on patient's journey;" (Baruch, 2012) Participants also spoke about how Living Well provided them with the opportunity to see people in situations that were even more difficult than their own. Because the program welcomed participants in many stages of illness, and with different types of illnesses, it provided exposure for people, and in many created a chance to feel grateful. (Broduer) Involvement in the TMV intervention changed the AYAs' focus from self toward more positive perspectives, such as altruism (Burns et al., 2010) This often overlapped with the theme of the importance of meeting other HIV' young people to share experiences and being reassured that their experience was not unique: (Campbell et al., 2010) Camp exposed them to different ways of	"Well, I haven't got it in many places so I thought that I was lucky because other people have got it worse." (Barlow et al., 1999) "I realized that it isn't the end of the world." (Barnetz et al., 2012) "I feel less scared now. I feel not as worried about the future as I did before. I know that I am not the only one with it and that I can do most things that other people can do but just need to be careful. I know that I have somewhere to talk about things, although I can talk to my aunt, it is good to talk to people my age as well and be open about things. I feel better about managing and looking after myself in the future, but know that it will depend on the situation." (Campbell et al., 2010) "Camp has really affected my life in many ways. I mean, I think the number one way it's affected my life is now I've learned about a bunch of people who have gone through what I've gone through and that they can continue living their life like a normal human being without having to think about all they've been through. And it makes you realize what	Barlow et al., 1999, Barnetz et al., 2012, Baruch, 2012, Brodeur, 2005, Burns et al., 2010, Campbell et al., 2010, Gillard et al., 2011/13/16, Lewis et al., 2016, Moola et al., 2015, Nicholas et al., 2007, Stewart et al., 2011b/13, White, 2014,

Theme: A New Normal			
	thinking, different attitudes, and different experiences through their interactions with others. (Gillard et al., 2011) Comparing himself to other campers, a focus group participant explained, “I see so many different things here, like if it's [people from different] cultures or kids that have had it worse than you. It makes you appreciate what you've had.” (Gillard et al., 2013) Similarly, another camper spoke about how being around people who are going through the same experience has helped him realize important things about himself. (Gillard et al., 2016) Parents and ChIPS co-ordinators also spoke of observing the young people’s strength of character and the capacity for ChIPS to engender a buoyant, positive attitude that flowed into daily life. (Lewis et al., 2016) Many youth suggested that their camp dialogues allowed them to ‘put things into perspective’, and to realize that other youth face far more formidable health challenges (Moola et al., 2015) They were permitted different vantage points and tools for articulating, reconsidering and managing circumstances (Nicholas et al., 2007) For seven participants, self-awareness was enhanced through social comparison. (Stewart et al., 2011b) In	everyone else is going through and that your life isn't so bad.” (Gillard et al., 2016) “I guess it puts it more into perspective about how you might not necessarily have it the worst, like out of everyone. I guess appreciate – like I wouldn’t say life – but you appreciate your situation a bit more. I think it (camp) was a good for me. I think especially because when I was first diagnosed and I couldn’t play sports and that was grade nine. I was like really mad every day, I was so mad for like a whole year, yeah. It was a good to see like ‘maybe sports isn’t everything, it’s not everything in the world’ and some people, they can’t even like run around with their friends. It’s not necessarily the worst, thing that could happen. It put things into better perspective.” (Moola et al., 2015) “It gave me a different way of looking at life through other people’s eyes” [CP-09]. (Stewart et al., 2011b)	

Theme: A New Normal				
	the post-test interviews, a few children empathized with other children who had more difficult problems to handle....Children described instances of both upward and downward social comparison in the online support group for improved reactions and response to asthma and allergies. Some children compared themselves to other children who had asthma and allergies which were difficult to control and said this made them more comfortable and confident (Stewart et al., 2013a) This would allow their children to realize that others have gone through similar life and health experiences, and to see that other children also have limitations. (White, 2014)			
Feeling special as result of an intervention	The program is associated with “pride” and it was referred to as a “special club” with a “code” that “you can only compare	”But no, every single kid was made to feel unbelievably special in their own way.” (Gillard et al.,	Baruch, 2012, Desai et al., 2014, Gillard et	Adapting intervention?

Theme: A New Normal			
	it with someone who went through the same thing. (Baruch, 2012) Participants consistently approved that being recognized for their special talents at the closing event felt ‘good . . . cause it makes you know that you have done something cool.’ (Desai et al., 2014) Children appreciated that it was made specifically for them (Marsac et al., 2012) Furthermore, interviewees said that the positive portrayal of their son or daughter had allowed friends and family to see the child was ‘more than a sick kid’ and instead ‘a normal person who was being strong in a difficult situation’. This in turn generated expressions of admiration that left parents feeling ‘genuinely understood’ and the paediatric patient ‘brave and special’. (Shrimpton et al., 2013) Omar’s mother explained the significance that this special activity had for her son. She said, “I don’t want his sister or brother to be in a private karate class. This has really helped him a lot. Even during the week when they do things that he can’t do, we mention the karate thing. I tell him that he does karate and they don’t.” (Wright et al., 2004)	2013)	al., 2013, Marsac et al., 2012, Shrimpton et al., 2013, Wright et al., 2004,
Feeling stigmatized through taking part in an intervention			O’Callaghan et al., 2012

Theme: Mutuality				
Idea for further interpretation/ Third Order Construct	Second Order Construct	Quote	Papers contributing	Acknowledgement of overlap
Mutuality: needs element of recognition?(CYP have something to offer to designing intervention, each bring something to relationship, learning from each other/teaching others or empathy for each other, something positive to bring to interactions)	Regardless of the target audience, this study has illustrated that consulting the ‘experts’ should help to ensure that the content, style and format is not only relevant, but also salient to children and their parents. (Barlow et al., 1999) They expressed a sense of mutuality in the relationship. The mentees reported on a high sense of intimacy, of knowing their mentor well, of a special kind of friend: I know him no less than he knows me, I help him, he doesn’t only help me. (Barnetz et al., 2012) They also saw themselves as able to give information to help other children. As one female, age 12, pointed out, "Well, Kim is on the kind of therapy now that just finished, so now she can come to me and ask me what it's like, and I can tell her.' (Bluebond-Langer et al., 1991 Langer) Being available for support during new cardiac surgeries Feeling important and needed (Desai et al., 2014) For example, as was articulated by a camper, if children need additional heart surgery to revise the cardiac repairs completed during early childhood years, friends developed through camp might become a valuable source of support. (Desai et al., 2014) The relationship worked both ways. A social	There was consensus among the children that they were ‘the experts’ and they felt that they should be consulted in the development of psychoeducational interventions for the future. The strength with which children expressed these views was very clearly observable to the focus group moderators. As one child said: “You’ve really got to ask people like us what we want...otherwise you’ve just got a load of people who think they know about arthritis. It doesn’t work... It’s not doing anything for anyone.” (Barlow et al., 1999) “...But then when Living Well came along, it’s like people want to be bothered like, I guess. Whether they want to learn from you or help their self, there are people out there that want to know….”(Brodeur, 2005) “I thought [the techniques] were helpful and something I would want to teach my sister’’ (Bignall et al., 2015) “He actually recognized that he was in part of a study, so he thought that was pretty cool by this time, we had done months and months and months of chemo,I so he felt like he was contributing, where before he	Barlow et al., 1999, Barnetz et al., 2012, Bignall et al., 2015, Bluebond-Langer et al., 1991, Brodeur, 2005, Burns et al., 2010, Desai et al., 2014, Gillard et al., 2011/13, Kashikar-Zuck et al., 2016, Kirk et al., 2016, Lewis et al., 2016, Muskat et al., 2016, Nicholas et al., 2007, Serlachius et al., 2012, Shrimpton et al., 2013, Stewart et al., 2011b/13, Tiemans et al., 2007, Wright et al., 2004,	Empowerment, self-esteem, hope and inspiration. Informational/Emotional support, Therapeutic Relationships.

Theme: Mutuality			
	worker explained: "It gives me the opportunity to see them outside of their clinic visit. It gives me the opportunity to learn about them on a more intimate level and have them see me as more than just the social worker in the clinic. They see me and they want to talk to me, and it's more of a relaxed atmosphere." (Gillard et al., 2013) An arts and crafts director shared the story of some boys who donned pirate eye patches in solidarity with another boy who had sustained an eye injury during camp. (Gillard et al., 2013) They exchanged experientially derived advice and views on their strategies for managing treatments, emotions, relationships, identity and support from services, often giving detailed descriptions of how they had personally managed different situations. (Kashikar-Zuck et al., 2016) They exchanged experientially derived advice and views on their strategies for managing treatments, emotions, relationships, identity and support from services, often giving detailed descriptions of how they had personally managed different situations. (Kirk et al., 2016) Many support groups are founded on principles of mutual aid. Mutual aid positions member-to-member support and assistance as vital in the helping process as well as asserts that some types of help are	was always looking at other people's statistics, and I was too." (Mother; son, 14 years old) (Burns et al., 2010) While reflecting on the photograph of his cabin mate, a 12-year-old participant conveyed that his cabin mate's parents reached out to him for peer support when their child needed more heart surgery. He said, 'His parents wanted me to . . . give him some advice and help him relate to how it is going to be. That really makes me feel important . . . I get to share my life experience and relate to him with his life experience.' (Desai et al., 2014) We were able to see how they were doing the exercises) and encourage each other. (Kashikar-Zuck et al., 2016) [ChIPS] works on a connection model, it works on a model where support is available or demonstrated and it works on a trust relationship where vulnerabilities can be discussed and where coping with or adapting to the life that you lead as an adolescent with an illness is able to be validated, both through the difficulties and also through some of the resilience that you build up. So for me, ChIPS is around young people supporting young people.(Lewis et al., 2016)	

	Theme: Mutuality		
	better received when coming from a peer rather than from a group leader...Mutual aid is considered an important process in social work support groups. It refers to the phenomenon created in groups where members are both recipients and providers of help (Shulman, 2006; Steinberg, 2014). It is based on principles asserting that group members have strengths, perspectives, information, and experiences that can be drawn upon to help one another, and thus themselves.(Muskat et al., 2016) Participants suggested increasing peer interaction in the programme, and swapping ideas on how to manage problems. (Serlachius et al., 2012) Many of these parents relayed how their child's friends were also taken by the antics and humour of the personalised movies, which provided 'cool things to talk about' and so helped the child to feel they had something new, creative and positive to contribute in their interactions with friends. (Shrimpton et al., 2013) Many of these parents relayed how their child's friends were also taken by the antics and humour of the personalised movies, which provided 'cool things to talk about' and so helped the child to feel they had something new, creative and positive to contribute in their interactions with friends. (Shrimpton et al., 2013) They believed they received and provided practical information that made them feel	In another instance, computer-mediated interaction was seen as a means of promoting mastery and confidence, as illustrated below. "I think it encouraged (the ill adolescent) ...to know that he had the ability to 'do.' I think it really boosted his confidence, knowing that he had something to offer other kids, and that someone saw that while he was on the computer. I think that it made him happy to think that he might be able to give to somebody. So I would say that it really gave him a boost in his confidence, which is a real important thing." (Nicholas et al., 2007) The intervention was described as "a learning experience, and a way to meet people with the same disability, and to share the knowledge that they possess with you, for you to share what you know with them." (Stewart et al., 2011b) "think the main thing about that group was that because we all went through tough times. ...We have all gone through the same thing, we all have compassion for each other." (Tiemans et al., 2007)	

Theme: Mutuality		
	more comfortable about managing their asthma and allergies. (Stewart et al., 2013a) Mentors thought that all children were engaged, contributed, and felt important, “everyone else feels like their ideas were really cool.” (Stewart et al., 2013a)The fourth PSRM responsibility level, helping others, seemed particularly relevant to participants. This level includes leadership, empathy, and teaching. Children with disabilities often have unsuccessful experiences in sport and physical activity. It is a rare but salient experience for many of them to see themselves as a role model or leader in such a setting (Wright et al., 2004, 2001, 2002) (Wright et al., 2004)	

Theme: Managing Myself

Theme: Managing Myself				
Idea for further interpretation/ Third Order Construct	Second Order Construct	Quote	Papers contributing	Acknowledgement of overlap
Link between physical and mental health	Most participants also demonstrated understanding of how the coping skills and physical exercise portions of the intervention were complementary (combined treatment). (Kashikar-Zuck et al., 2016) Even though they experienced the educational part of the intervention as complicated and difficult to understand, as illustrated by YP3: 'I get the basic idea about the adrenaline loops and things like that, but I don't understand how that affects the body and things like that', others still considered this part necessary and helpful: 'It made a lot of sense to me actually' (YP4). (Reme et al., 2013)	"The body questions really make me aware of how much my body is affected by stress" (Whittemore et al. 2010)	Kashikar-Zuck et al., 2016 Reme et al., 2013 Whittemore et al., (2010)	More than Just My Illness

Theme: Managing Myself				
Managing LTC/Link to making more confidence/taking responsibility for managing physical symptoms/side effects	Thus participants (child and/ or parent) will perceive greater confidence in their Psycho-educational interventions in JCA abilities to control or manage various aspects of JCA (e.g. pain, emotional impact, daily activities) (Barlow et al., 1999) Many mentees reported another type of learning that included the specific skills associated with the day-to-day coping with diabetes, and is connected with insulin injections, nutrition, using a pump, and so forth. (Barnetz et al., 2012) the intervention group generally had a positive experience, reporting that the intervention was ‘‘helpful’’ or made them ‘‘feel better’’ in terms of both asthma symptoms and psychosocial functioning (Bignall et al., 2015) The children exchanged information, not only about medical issues, but also about how to cope with their disease and it calment. (Bluebond-Langer et al., 1991) The behavioural aspects of the therapy emerged as being particularly valued and accepted by the young people who found these easy to ‘latch on to’. Help with setting goals for physical activity, and implementing sleep routines were frequently cited as the most useful aspects. Indeed, this was often perceived as the key element in helping to combat CFS. (Dennison et al., 2010) These included developing activity related skills, building self-sufficient attitudes, increasing self-esteem, engaging in activities	“The mentor told me how to avoid injecting into the muscle. The mentor taught me how to inject. I was too scared at first but he explained it to me with a pen and afterwards with a syringe. The mentor taught me how to use an insulin pump. The mentor taught me a lot about carbohydrates and food quality, when it’s better to eat what. I’ve got an insulin pump today, thanks to the mentor. The mentor taught me to inject into my belly and my leg, and she taught my mom too.” (Barnetz et al., 2012) “I feel happier and know that I am not alone and I am not afraid anymore. I feel less scared now. I feel not as worried about the future as I did before. I know that I am not the only one with it and that I can do most things that other people can do but just need to be careful. I know that I have somewhere to talk about things, although I can talk to my aunt, it is good to talk to people my age as well and be open about things. I feel better about managing and looking after myself in the future, but know that it will depend on the	Barlow et al., 1999, Barnetz et al., 2012, Bignall et al., 2015, Bluebond-Langer et al., 1991 Dennison et al., 2010, Desai et al., 2014, Fair et al., 2012, Gillard et al., 2011, Hosek et al., 2012, Jaser et al., 2014, Kashikar-Zuck et al., 2016, Kirk et al., 2016, Nicholas et al., 2007/09, Nieto, Marsac et al., 2012, Muskat et al., 2016, Nicholas et al., 2007, Reme et al., 2013, Serlachius et al., 2012, Sibinga et al., 2011, Stewart et al., 2013a, Wolf-Bordonaro, 2003	Involving parents/behavioural aspects

Theme: Managing Myself		
	that encourage a sense of mastery and efficacy in peer relationships, and learning about their medical condition through formal education, or informal peer interactions (Desai et al., 2014) Issues such as taking medications during a sleepover, telling a teacher not to help clean a cut knee, and disclosing to a potential sexual partner were discussed. (Fair et al., 2012) These categories included anger and conflict management, disclosure, skill learning and education, and medication adherence. (Gillard et al., 2011) My perfect program wouldn't just not only be focused on the infection. ..Sexuality education. The participants strongly emphasized the need for sexuality education that extends beyond ''just bringing no babies home.'' They suggested that interventions should focus on re-exposure to HIV, sexually transmitted infections and their consequences, teaching women how to use female condoms, and preparing them for condom negotiation.(Hosek et al., 2012) Lastly, parents and adolescents both reported that PA helped with diabetes self-management. (Jaser et al., 2014) Although the young people posted queries relating to the management of medications/therapies, (Kirk et al., 2016) Children learned specific techniques such as breathing, distraction, and talking to their parents; (Marsac et al., 2012) Medication adherence is critically important to	situation." (Campbell et al., 2010) "I have learned to eat healthier because before I came to camp I used to eat up a lot of junk food. And I still do, but I keep myself on a diet kind of like." (Desai et al., 2014) As one parent stated, ''reminders and gifts helped remind her about taking care of diabetes and helped make it habitual.'' (Jaser et al., 2014) As one adolescent reported, ''It made me realize to keep checking (blood glucose) in the back of my mind.'' (Jaser et al., 2014) "They also gave me ideas of how to do things exercises on my own...so I found out a new way to do that modified crunches and love it." (Kashikar-Zuck et al., 2016) One child reported, "(I use the Cellie Kit) when I'm not feeling well… I look through it and try to see if there are any cards that could help… and I try it." (Marsac et al., 2012) "I learned things about, like I thought HIV and AIDS were two separate things but then they told me if you have HIV you can

Theme: Managing Myself			
	the health of children and teens living with HIV, yet it has often been found to be problematic for this population. The majority of group participants reported that they discussed treatment and medication-related issues regularly in the groups. They also spoke about how the groups helped them adhere to treatment routines. As one younger group participant reported,...Participants described that they discussed the importance of medication in the groups and that having and giving peer support enhanced their willingness to take medication.(Muskat et al., 2016) Online network participation was designed to increase health-related knowledge (e.g., condition-specific, general health issues)...For example, a child described receiving help in handling injections/needles.(Nicholas07) while the remaining seven reported that they were very satisfied with the treatment and that they were either much or very much better....the behavioural aspects appeared most important for symptom improvement and recovery. (Reme et al., 2013) The advantages of including diabetes-specific information were discussed across all groups by six participants. Participants reported wanting to clarify and refresh their understanding of diabetes and self-management skills. ...Another theme across all groups was the desire for more diabetes-specific information and skills.(Serlachius et al., 2012) Additionally, several of the HIV-positive	get AIDS so they told me like medication, like before medication and stuff like that was a joke, like I didn't take it seriously and now I take it really really seriously…"(Muskat et al., 2016) "I did bronze camp down at Lorne and the instructor was a diabetic. And he could tell instantly when I was having a hypo, and he just gave me all these tips which has really helped."(Serlachius et al., 2012) One child reported, "(I use the Cellie Kit) when I'm not feeling well… I look through it and try to see if there are any cards that could help… and I try it." (Marsac et al., 2012) "And that's what it was like coming here too, cause it helped me, it helped me a lot. Especially cause I always had to ask how do I get it again, how do I transmit it, and yeah cause I always had to ask the second questions because I always have to make sure that I'm at a point where if someone asked me, I'm ready to answer their questions." (Muskat et al., 2016) For example, one 9-year-old boy related, "Every meeting I learned	

Theme: Managing Myself		
	participants suggested that their ability to take their antiretroviral medicines increased as a result of their participation in the MBSR program. One (1) participant reported that her viral load had become undetectable as a result of her increased adherence (Sibinga et al., 2011) Information Support. The children gave concrete examples of information support including learning about triggers such as the benefits of allergen avoidance and new strategies such as placing asthma medication on night tables so “I don’t forget” (Stewart et al., 2013a) Preliminary efficacy findings demonstrate the potential of the TEENCOPE intervention to improve The Elimi-Pain Game was the strongest intervention for the provision of accurate and appropriate information to the subjects. In addition to the game’s drawing tasks and abstract representation of pain tasks, the game cards asked direct questions about SCD treatment, symptoms, and prophylactic initiatives. Each subject gained empowering information about their disease, and steps they could take to prevent SCD crisis. (Wolf-Bordonaro, 2003)	new things about how to manage my asthma. I sometimes wheeze—so my mentor told me about what she does. Well my asthma has been better.” (Stewart et al., 2013a)

Theme: Managing Myself			
Sense of control/looking forward	The desire to understand more about the wider impact of JCA and to enhance self-management ability is in accordance with studies of adults with arthritis...Children felt that if they were informed in advance about the possibility of being teased and bullied because they 'look different' they could begin to develop coping strategies.(Barlow et al., 1999) The idea of therapy as a 'starting block' on a gradual journey to recovery was often mentioned. Specific benefits included a creative outlet, sense of control, connectedness with others, and alleviation of symptom distress. (Burns et al., 2010) 'It gave me something to work with which is something I haven't had since I was in school. (Dennison et al., 2010) The participants suggested ways of incorporating empowerment principles into a secondary prevention that included building their self confidence by teaching life-skills and decision making skills to empower young women to thrive in their community and live out their dreams....While behavioral scientists may not be able to change the environment in which young HIV-positive women live, they can empower them with the knowledge, skills, and tools to better cope with daily challenges, develop healthy relationships, and promote self-worth and self-confidence as these critical competencies have the potential to reduce risky behavior. (Hosek et al., 2012)	"I'd like to know what could happen, so you've got no surprises later on." (Barlow et al., 1999) ''Learning the techniques helped my asthma and me as a person, because if I know how to control my asthma now, I can help in the future and stop things from occurring.''(Bignall et al., 2015) "Confidence, teach her how to be in society. Teach her how to thrive in, survive on her own in the real world, not just dealing with her own issues but how to deal with career goals, how to market yourself, how to just put yourself out there." (Chicago) (Hosek et al., 2012)	Barlow et al., 1999, Bignall et al., 2015, Burns et al., 2010, Hosek et al., 2012, Dennison et al., 2010, Nicholas -07

	Theme: Managing Myself	
	Support in this context encompassed distraction, education and peer contact; all of which appeared to cumulatively yield outcomes of increased control, mastery and coping. (Nicholas et al., 2007)	

Theme: Managing Myself				
Stress/Emotions management/MH symptom relief./Cope with illness or stigma	Content of future psycho-educational interventions Essential disease-related information (e.g. aetiology, symptoms) Treatment-related information (e.g. medication, exercise, use of aids) Side-effects of treatment Time commitment needed Psychological and social impact Self-management strategies (e.g. relaxation, cognitive pain management) Assertiveness training for parents and children Communication skills for children, parents and health professionals Social skills training, particularly for children(Barlow et al., 1999) others about dealing with emotional or social problems such as behavioral patterns around diabetes.(Barnetz et al., 2012) Developing coping skills/common challenges (Desai et al., 2014) Parents also provided insights regarding benefits of the TMV to promote positive coping through the use of confrontive coping strategies. (Docherty et al., 2013) The BIFI-A is also designed to foster skill building around goal setting, stress management and problem-solving...Supportive interventions are incorporated to address issues around grief, emotional recovery, coping with loss and change and affective (emotional) communication. (Gan et al., 2010) These categories included anger and conflict management, disclosure, skill learning and	"it feels good...it can show happiness;" and child (002) "when I'm feeling sad they make me happy;" and child (004) "makes me happy, brings a smile." (Baruch, 2012) ''It actually works, I can calm down when angry'' ''Just to relax and wanted to breathe'' 'I was getting mad over some petty stuff, did it to calm down'' ''It was great, I feel a lot better. Helped me feel better and deal with my stress'' (Bignall et al., 2015) "It made both of us stronger. She's more open now. She can cope with it a little bit more, I think." Participant #6 - M other - Post-Interview, pg. 3(Brodeur, 2005) "it made me consider what I would do if I was in a relationship. Would I tell them? I suppose not. Keep it cool because you don't want to bring up the situation. Learn to trust them, love them. Eventually it comes out in the open. Take time. You just can't tell them. "Your condition is a secret because you need to learn to trust them. If you just fall out	Barlow et al., 1999, Baruch, 2012, Brodeur, 2005, Bignall et al., 2015, Barnetz et al., 2012, Campbell et al., 2010, Desai et al., 2014, Docherty et al., 2013, Gan et al., 2010, Gillard et al., 2011/Hosek et al., 2012, Jaser et al., 2014, Kashikar-Zuck et al., 2016, Kirk et al., 2016, Marsac et al., 2012, Muskat et al., 2016, Nicholas et al., 2007, O'Callaghan, Serlachius et al., 2012, Sibinga et al., 2011, Shrimpton et al., 2013, Stewart et al., 2011b/, Whittemore et al. 2010, Weekes et al., 1993,	Transitional object

Theme: Managing Myself			
	education, and medication adherence. (Gillard et al., 2011) Virtually all of the participants acknowledged that young women will inevitably continue to face disappointment, rejection and lack of support, but that an intervention could provide young women with the knowledge and skills they needed to better handle those situations when they arise. (Hosek et al., 2012) More than half of adolescents reported that they used PA exercises during the course of the study (n = 11/20 interviewed), primarily when they were upset, stressed, or sad or when checking their blood glucose level. (Jaser et al., 2014) Participants shared strategies they themselves had found helpful in managing negative emotions, which included sharing feelings with others, being positive and living in the present. (Kirk et al., 2016) Families used the Cellie Kit for psychoeducation and/or to learn new ideas for coping, to normalize experiences, to gather information, to initiate conversations, for fun, to promote emotional expression, and for general comfort. (Marsac et al., 2012) Accordingly, all participants stated that online participation offered psychosocial support to hospitalized children.... Finally, the replication of earlier findings in the literature strengthens the contention that this type of online intervention potentially contributes to important child health outcomes such as enhanced self-esteem and	there’s no point telling them then the relationship is over.” (Campbell et al., 2010) “Mom was over-protective after my injury because she was worried about me [teen 5]. .. . that my mom and dad get stressed out too and I learned some things to try to calm down when I am frustrated”(Gan et al., 2010) Adolescents also reported that self-affirmations were helpful. One adolescent stated that when he was upset, he ‘‘thought about what I was proud of or what made me happy, which helped me to calm down and be happy again.’’(Jaser et al., 2014) “They coping skills actually got me through some of the exercises some days. When I was getting... tired... or... frustrated, when I was learning new exercises and I wasn't quite doing them right... I would...stop and relax do a mini-relaxation) and get a drink of water and then go try it again” (Kashikar-Zuck et al., 2016) “Like strategies, or ways to deal with the public thing. Like developing a skill where you stop worrying about what strangers	

Theme: Managing Myself			
	reduced depression (Burgos, Robinson, & Lin, 2000). (Nicholas et al., 2007) accompaniment Leila calmed, stopped crying, displayed regulated breathing, a brighter mood, and increased engagement with others. Her mother also found the music “calming” as she rocked Leila in her arms....Therapists’ singing of live familiar songs for patients in procedures like lumbar punctures, scans, venepunctures, and central line changes have also prevented the need for sedation. The session is like a “bubble” where protection is offered, containing, holding, and easing a child’s distress. (O’Callaghan et al., 2013). ..Prior to surgery for a tumor biopsy, five-year-old Mary used the duck and whale castanets to denote entering a dark, scary forest where she couldn’t find her friends. Mary felt lost, alone, and scared, and wondered why her friends were not with her. The music therapist asked whether there was something she could do when feeling scared. “Sing,” Mary responded. They then sang, “Five little whales” and “Five little ducks” numerous times. In the songs the baby animals leave their mothers for some time but then all “come back.” There was a positive change in Mary’s affect whilst singing and playing the castanets which, arguably, helped Mary to enter theatre in a more relaxed state.(O’Callaghan et al., 2013) reinforces the importance of giving adolescents a ‘toolkit’ of skills to help them	would think, for example at the footy” (Serlachius et al., 2012) “It helped me so I wouldn’t get so mad all the time” (Stewart11) "I like to hold my morn's hand and dig my nails into someone, it's something to let my tensions out on." (Weekes et al., 1993) “Great stress relieving examples—I would try them all.” (Whittemore et al. 2010)	

	Theme: Managing Myself	
	more effectively manage with stress.(Serlachius et al., 2012) The general feeling among participants was that using the methods taught in the MBSR course helped them to feel more ‘‘calm’’ and ‘‘relaxed,’’ as well as more able to manage their anger and conflicts. For those who struggled with feeling anxious, the techniques were often used to feel ‘‘less stressed,’’ while those who struggled with sadness found the techniques to be helpful in terms of putting them in a more ‘‘cheerful mood,’’ or to ‘‘feel happier’’ and ‘‘less down.’’(Sibinga et al., 2011) even reported losing weight as a result of regular practice. However, others perceived that it was through the reduction of and/or management of stress related to MBSR participation that previously existing stress-related physical complaints were alleviated, such as headaches, jaw tightness, and nervous leg movements....mentioned as an important concern upon probing this issue. The MBSR methods seem to have a positive effect in terms of ameliorating HIV-specific stressors such as taking medicines, fearing illness and death, experiencing stigma and discrimination, and disclosing HIV status.(Sibinga et al., 2011) A brief case example helps to demonstrate how this seemed to occur for patients associated with our study. Pippa, a ‘scared’ and ‘distraught’ preschooler, was shown MMP videos produced by patients of a similar age. Seeing other children singing, dancing and	

Theme: Managing Myself

laughing as part of their radiotherapy-modelled positive coping behaviours (Shrimpton et al., 2013)

Another explanation is that for low income African-American youth, simply interacting with the research team and learning about asthma management had an immediate calming effect. (Bignall et al., 2015)

Moreover, the groups helped the attendees to cope with the stigma associated with HIV and in providing support for improved medication adherence. (Muskat et al., 2016)

Hand holding aided in reducing the tension associated with impending treatments (Weekes et al., 1993)

Theme: Managing Myself				
Emotional management factors unhelpful/Ineffective	Several young people reported disliking what they called the ‘psychological’ or ‘emotional’ aspects, finding them irrelevant or inappropriate. ‘It was quite a lot thought based. Umm, I didn’t think that it, umm, the psychology, I didn’t really think that really helped me’ (YP 1 2 CBT).(Dennison et al., 2010, CBT) Finally, our findings have revealed an apparent mismatch between the positive findings of our qualitative analysis and the stability of the survey findings, that is, that they showed no change in the young people’s self-esteem or psychological distress. We suspect that this is due to a short measure time, or perhaps our choice of survey.(Lewis et al., 2016)	“did not like coping skills group at all... when I sit down and talk to people about stuff I am going through...it's really hard” (Kashikar-Zuck et al., 2016)	Dennison et al., 2010, Lewis et al., 2016, Kashikar -Zuck	
Adoption of skills into daily life	Help with setting goals for physical activity, and implementing sleep routines were frequently cited as the most useful aspects. Indeed, this was often perceived as the key element in helping to combat CFS….Young people and parents both felt family involvement was important so that parents could understand the approach and be involved practically by implementing advice and strategies and enforcing rules.(Dennison et al., 2010) Additional training and materials may also improve adolescents’ and parents’ use of the PA exercises.(Jaser et al., 2014)I: How do you do that? P: For me, I’ve actually practiced it the other day. I was about to get in an argument. I just sat there and I took three	“Mini-relaxation I would do all the time when I felt a little tense... muscle relaxation I would usually do in the morning or at night before I went to bed. Pleasant imagery I usually did before bed or if I was having a lot of pain...calming statements...I did mostly when I felt...anxious or when I couldn't sleep.” (Kashikar-Zuck et al., 2016)	Dennison et al., 2010; Jaser et al., 2014, Kashikar-Zuck et al., 2016, Sibinga et al., 2011, Stewart et al., 2013a,	Improved relationships: Family involvement and need for training of family members. Keeping it Going

Theme: Managing Myself			
	breaths and did my own little counting in my head and took three more breaths. And I was actually calm and left the argument—just let it be. (Sibinga et al., 2011)These children incorporated practical strategies from their peers and mentors into their day-to-day coping.(Stewart et al., 2013a)		
Role of facilitator or link to professional: reassurance/tailoring	Nearly all participants reported that the pace and progression of learning exercises was a positive feature, (Kashikar-Zuck et al., 2016) There appeared to be some self-regulation of online communication in terms of the advice being provided. Indeed, participants would contradict the advice of others and also advise parents to contact health-care professionals. (Kirk et al., 2016)	“ You know what you are doing and how to hold positions before you move on to the next level...I learned how to do them right and better.” (Kashikar-Zuck et al., 2016) “Beyond these qualities, facilitators or peers should challenge the young women to extend beyond their comfort zones. It will help give them that extra push, like say, yeah, take them by their hand, walk them to where they need to be and maybe they need you to be there just that much to get them to start doing what they need to do.” (Hosek et al., 2012)	Kashikar-Zuck et al., 2016, Kirk et al., 2016, Hosek et al., 2012

Theme: Managing Myself				
Managing relationships with family/peers/support seeking	sense of isolation that often accompanies arthritis. Equally, raising awareness of the difficulties that may be experienced in social spheres combined with social skills training may assist children in negotiating their way through essential daily activities (e.g. attending school).(Barlow et al., 1999) These categories included anger and conflict management, disclosure, skill learning and education, and medication adherence. (Gillard et al., 2011) Participants raised the complexities surrounding disclosure that they faced on a daily basis. In particular, they were concerned about the impact of the disclosure of their status on their romantic relationships (Campbell et al., 2010) Campers experienced and recognized the psychosocial benefits of activities. A 14-year-old surmised, ‘The activities are team based that is basically to teach you helping skills and social skills I guess.’ (Desai et al., 2014) Adolescents also noted improved communication skills. A 16-year old female stated, “I got to talk to other kids so we could like ask questions and stuff. I’m better at talking to people now.” (Fair et al., 2012) Although campers wrestled with issues about disclosure, they gained technical skills regarding HIV/AIDS. This education included information about the HIV virus, taking and remembering to take medications, problem	“It made both of us stronger. She’s more open now. She can cope with it a little bit more, I think.” (Brodeur, 2005) One participant identified a strategy for disclosure based on the building of mutual trust: “.. . it made me consider what I would do if I was in a relationship. Would I tell them? I suppose not. Keep it cool because you don’t want to bring up the situation. Learn to trust them, love them. Eventually it comes out in the open. Take time. You just can’t tell them. Your condition is a secret because you need to learn to trust them. If you just fall out there’s no point telling them then the relationship is over.” (Campbell et al., 2010) Campers experienced and recognized the psychosocial benefits of activities. A 14-year-old surmised, “The activities are team based that is basically to teach you helping skills and social skills I guess.” (Desai et al., 2014) They discussed session topics, and understood their family more. “It just showed me how other people deal with their	Barlow et al., 1999, Brodeur, 2005, Campbell et al., 2010, Desai et al., 2014, Fair et al., 2012, Gillard et al., 2011, Hosek et al., 2012, Kirk et al., 2016, Marsac et al., 2012, Muskat et al., 2016, Nicholas et al., 2007, Serlachius et al., 2012, Sibinga et al., 2011, Stewart et al., 2011b/13,	Accessibility, Improved Relationships, Info/Emotional Support

Theme: Managing Myself			
	solving, and dating and relationships. (Gillard et al., 2011) The participants also reported that interventions developed for young women living with HIV should devote time to disclosure. Specifically, teaching young women ‘‘how to disclose and who to tell’’ by improving communication and learning to evaluate the risks and benefits of disclosure to others. Young women asked for activities that would help women to ‘‘stop and think’’ before they engage in sex with a partner of any type...Many described unhealthy and unsupportive relationships with friends, family and romantic partners yet lacked effective communication and relationship skills and coping strategies to protect themselves especially when it came to knowing when to disclose their HIV status or when and how to ‘‘keep the secret.’’ (Hosek et al., 2012) Some young people were experiencing bullying at school, and participants responded to these postings by sharing their own experiences and advising on different strategies to manage this situation. (Kirk et al., 2016) Children learned specific techniques such as breathing, distraction, and talking to their parents; (Marsac et al., 2012) help members find solutions to practical issues (i.e., disclosure strategies and relationship challenges), and (Muskat et al., 2016) conflict resolution was added to the	family members and kind of helps me.” (Stewart et al., 2011b)	

	Theme: Managing Myself	
	communications skills training module specifically to address the issue of parent/adolescent conflict; (Serlachius et al., 2012) have a positive effect in terms of ameliorating HIV-specific stressors such as taking medicines, fearing illness and death, experiencing stigma and discrimination, and disclosing HIV status.(Sibinga et al., 2011) They said that talking with their peers and mentors who have similar problems gave their children new skills to handle difficult social situations.(Stewart et al., 2013a)	

Theme: Managing Myself			
Activities leading to self-knowledge about what they were capable of achieving	Increases in specific developmental outcomes became a separate theme because campers and staff viewed them as personal changes to campers’ self-concept and self-efficacy, as influenced by their camp participation. (Gillard et al., 2011) I know what I can do and if I feel like there’s pain or I feel like I shouldn’t be doing this, I will let the teacher know and I will stop. (Moola et al., 2015) Lastly, Alicia suggests that her daughter acquired determination to participate in activities, and skills to be self-reliant: (White, 2014)	“The program kinda like made me kinda get to know myself better more than anything. They made you think about what you were like and what you were on the outside and the inside. It made you look at yourself and think about how you feel a lot.” (Brodeur, 2005)	Brodeur, 2005, Gillard et al., 2011, Moola et al., 2015, White 24

Theme: Managing Myself			
Opportunities to reflect/gain self-knowledge	This understanding of courage, and the process of helping the child become aware of their courage and mastery of a difficult situation is especially relevant when considering the more distal outcomes of resilience (Haase, 1987; Pearlin & Schooler, 1987). The fact that fewer children describe the BOC Program as a symbol of accomplishment might be directly related to where they are in their treatment journey, and the opportunities provided for them to either interact with others for social comparison to help them develop confidence or mastery in the midst of dealing with the very difficult experience of receiving treatment for cancer.(Baruch, 2012) The TMV intervention also was perceived as an age- appropriate and appealing way for the AYAs to reflect on their experiences: It helped her talk about it, which I think is so important when you're suffering from depression it really helped a lot. (Burns et al., 2010) Parents described how work with the interventionist in lyric writing and selection of photos/images was critical and supported AYA self-expression and reflection, overage... Parents clearly valued the unique opportunity for self-reflection afforded by the TMV. (Docherty et al., 2013) Based on the findings of this study, the following includes several recommendations for camps to consider for strategic planning efforts to optimize	"it feels different , knowing that I have something to remember;" child (004) "looking back and already seeing how much I've gone through;" child (005) the BOC Program "makes me remember;" and child (006) "helps me remember what happened. (Baruch, 2012)	Baruch, 2012, Burns et al., 2010, Docherty et al., 2013, Gillard et al., 2011

	Theme: Managing Myself	
	supportive developmental experiences for youth with cancer. First, camp should provide structured and facilitated activities that encourage campers to reflect on their challenges and successes in camp and in life. Given that campers increased their positive attitudes, perseverance, feelings of freedom, and sociability, camp could provide more intentional and structured opportunities for campers to reflect on the changes in their lives, especially for older and returning campers. (Gillard et al., 2011)	

Theme: Managing Myself				
Distraction	Helped alleviate symptom distress ...While the TMV intervention provided a diversion, From parents’ perspective, TMV intervention helped alleviate symptom distress, including pain, nausea, sleep disturbance, and mood: (Burns et al., 2010) included perspectives about intervention effectiveness in providing respite from daily suffering such as mitigation of physical symptoms, Parents indicated that the TMV was effective in alleviating symptoms, provided respite and distraction from daily suffering, and provided an antidote for the uncertainty that is pervasive during transplantation [20]. (Docherty et al., 2013) Although the activities were not overly challenging to youth, they were able to engage fully in them, become distracted from other concerns in their lives, and feel free of stress. (Gillard et al., 2011) Due to the tightly scheduled days, constant activity, and high levels of excitement, campers were often too busy to focus on the negative aspects of cancer. (Gillard et al., 2013) In study 1 (Cellie Kit comments), children reported that they would use the Cellie Kit for emotional expression, to practice techniques for talking to others about cancer, as a toy for fun, for comfort, and for distraction during procedures....Children learned specific techniques such as breathing, distraction, and talking to their parents; (Marsac et al., 2012) In contrast, researchers, clinicians and	“How would you say that Living Well impacted you as an individual? P: What I liked about it, for the two hours we were there, I don’t know if this has impacted me as an individual or whatever, but I forgot I was sick. And I thought about the other people around me and what was wrong with them. And that was nice. Then you leave and you get back in your truck or your car and you drive home and you’re sick. But it’s nice to forget you’re sick. You’re so concentrated on the other person being sick, you know, that you forget. I know this sounds crappy, but sometimes I like it when my daughter gets sick because I worry about her and am so concentrated on her that I forget (about her illness). And you don’t get to forget very often.” (Brodeur, 2005) “When [the music therapist] would walk in the door, he would perk up, and he wouldn’t last too long, but at least it was a, BOh, how wonderful she’s here![So that was like a complete diversion from pain. A lot of times, he would be completely exhausted afterward	Brodeur, 2005, Burns et al., 2010, Docherty et al., 2013, Gillard et al., 2011/13, Marsac et al., 2012, Moola et al., 2015, Nicholas et al., 2007, O’Callaghan et al., 2013, Shrimpton et al., 2013, Weekes et al., 1993	Unconstrained

Theme: Managing Myself			
	programmers often assume that camp distracts youth from illness related thoughts – giving them a 'break'– from what are thought to be painful or traumatic experiences (Moola et al., 2015) Participants described the online network as an enjoyable distraction. According to one participant: "it just gives another option of things to do during the day (while in hospital). (Nicholas et al., 2007) Music can provide security, reassurance, relief from boredom, and opportunities for choice and control, without requiring concentrated effort or verbal comprehension: communication occurs through meanings associated with melodic inflexions and timbres....Music therapy can enable catharsis, self-expression, diversion, distraction from symptoms, and invasive procedures, aesthetic experience, a sense of achievement, important communication, and, very importantly, humor. (O'Callaghan et al., 2013) One of the most commonly reported outcomes of the MMP (n=16) was that the programme had been highly effective as a cognitive/attentional distraction....Meanwhile, the MMP-assisted children who were frightened of radiotherapy to redirect their attention to movie planning and production tasks (eg, discussing storylines, choosing music and filming and editing footage) that were viewed as 'exciting' and 'fun'....For other children, overwhelmed by diagnosis, hospitalisation and cancer treatment	and would sleep really, really well, so that was very, very nice." (Burns et al., 2010) one camper discussed his counselor: "He's the coolest guy ever! We played ball the whole time and I forgot I had cancer!" (Gillard et al., 2013) Attentional distraction "It was a great diversion … something enjoyable to look forward to when they're doing something that's not particularly fun. It was exciting for her to be sourcing props, talking about each next step (of the movie) … and all the time not be scared by the treatment, it took her mind off it completely." (Shrimpton et al., 2013) The statement of a 17-year-old girl with ALL clearly articulates the importance of distraction, She stated "It's hard, I hate it (the LP). It's hard to get The to go in there (the treatment room), I'm crying and trying to beg everybody to not do it. Having someone hold my hand makes it easier, gets my mind of what's happening." (Weekes et al., 1993)	

	Theme: Managing Myself	
	processes, the MMP successfully provided a ‘desperately needed’ distraction from the ongoing distress caused by these experiences...Pippa’s mother noted how the production of the video provided a much-anticipated distraction from the seriousness and discomfort of daily radiotherapy, (Shrimpton et al., 2013) The findings from this study indicate that subjects in both the cancer and the renal disease group believed hand holding to be an effective coping strategy in ameliorating treatment related pain. ... was a means of distraction, ...Distraction was the third function of hand holding, and was most wanted at the point of needle insertion. Adolescents reported that having a hand to hold helped to take their mind off the treatment. (Weekes et al., 1993)	

Theme: Empowerment				
Idea for further interpretation/ Third Order Construct	Second Order Construct	Quote	Papers contributing	Acknowledgement of overlap
Parents facilitate attendance/CYP have choice to attend	Receiving a personally addressed invitation letter and event programme was identified as important by several participants and may have reflected a growing...However, attendance at the event also required support and affirmation by family and/or health professionals and practical help, e.g., dropping off the young person at the venue (Campbell et al., 2010) Parents supported and encouraged engagement in therapy and were often responsible for initiating it. (Dennison et al., 2010) Researcher: How did you hear about ChIPS and how did you get involved? Girl 3: my mum Girl 1: I don't know, I can't Reme et al., 2013mber (Lewis et al., 2016) Group attendance was voluntary, which has been shown to result in more positive outcomes (Behroozi, 1993). (Muskat et al., 2016)	"I would say probably number one, get the parents on board. help them realize that this is going to benefit them, that this is going to help their kids and help them. I think that if you don't have support at home, it's not going to fly. . ." (Fair et al., 2012) Parental caregivers of group attendees reported that their children attended group because they wanted to. According to one parental caregiver, "Well I never put pressure and didn't say you have to go, it's not mandatory that you go, it's not like school, so and they were always willing to do it." Another caregiver reinforced that group attendance was voluntary, "She could attend it if she wanted to or, she didn't have to if she felt she didn't want to go to it. She wasn't being forced in any way shape or form. (Muskat et al., 2016)	Campbell et al., 2010, Dennison et al., 2010, Fair et al., 2012, Lewis et al., 2016, Muskat et al., 2016	Accessibility

Theme: Empowerment				
How want people to interact with me/help me.	centers on how parents understood and valued their AYA's need for privacy, autonomy, and opportunities to exercise independence and the ways in which the TMV intervention helped them honor and support these fundamental needs....The intervention was designed to create a supportive, structured environment that would give AYA opportunities to experience autonomy and independent decision making regarding the music, topics for the video, whether to involve family, friends, or care providers in the production process, and once completed, who would view it. (Docherty et al., 2013) Subthemes included honoring and valuing AYA privacy needs related to DVD creation and respect for AYA decisions regarding who would view the DVD. (Docherty et al., 2013) strategies for living with long-term conditions with peers and develop the expertise to empower them in interactions with health-care professionals. (Kirk et al., 2016) Once the assessment was completed, a decision was made to handhold or to refrain from handhold (Weekes et al., 1993) On two occasions during the intervention phase protocol, subjects invited third parties to participate in the Elimi-Pain Game. Subject 2 invited her young roommate; Subject 3 invited her brother. In both cases, the sessions were not interrupted by the participation of unexpected others....The Environment Collage intervention provided occasions for subjects to make	An interesting management technique already mentioned was a needle plan. The child's parent described how the needle plan was developed and used: "We did work out a strategy. It came from a birth plan. [The child] wrote out a needle plan, and she talked it through at home and worked it out with the psychotherapist here at the hospital. They did a 7-point plan. I think it read: 'don't tell me to be brave, I've been brave for ten years' and 'allow me to scream as much as I like. It helps me', whereas people would tell her to calm down when she couldn't. 'Don't tell me to turn away, I need to see what you're doing' and 'I'll tell you when I'm ready, don't go until I'm ready'. It was just sort of a 7-point plan. She had it written on a card, and every time there was a new nurse or doctor she'd hand the card to them and they had to read it before going near her." (P14:Mother).(Ayres et al., 2011) The mentor manages to come into both worlds, the world of the adults and the world of my worries, he knows them, you can choose what to share with him	Ayres et al., 2011, Barnetz et al., 2012, Gillard et al., 2013, Docherty et al., 2013, Kirk et al., 2016, Weekes et al., 1993, Wolf-Bordonaro, 2003	Ayres et al., 2011, Barnetz et al., 2012, Gillard et al., 2013, Docherty et al., 2013, Kirk et al., 2016, Nicholas et al., 2007, Reme et al., 2013, Stewart et al., 2011b/13, Weekes et al., 1993, White, 2014, Wolf-Bordonaro, 2003

Theme: Empowerment			
	more than creative choices. It permitted the subjects to act out control over the hospital environment; subjects were given unique opportunities to give verbal orders to their caregivers, fellow patients, or family members. The opportunities for perceived control seemed to be the most important benefit of the environmental collage intervention. (Wolf-Bordonaro, 2003)	and what not to share, (Barnetz et al., 2012) Campers discussed how most counselors treated them: “They're not over-protective. If something's wrong, they'll be like ‘Well, do you want to do this or go here?’ They give you a choice.” (Gillard et al., 2013)	

Theme: Empowerment				
Empower in asking for support/in relationship with staff/peers	Three teens thought increased confidence made it easier to “reach out” to able-bodied peers. (Stewart et al., 2011b) By sharing their experiences, listening to peers’ experiences, and role playing, the children were introduced to practical skills like problem solving, communicating, positive ways of educating others, seeking support, and advocating for themselves. (Stewart et al., 2013a) The researcher had an interesting opportunity to observe the assimilation of new information by one of the subjects. As reported in the Appendix K, the researcher escorted Subject 1 to her room following the Elimi-Pain Game. Upon reaching her room, Subject 1 stated she felt dizzy and required help to get into bed. The art therapist asked if she had eaten that day. Subject 1 explained that she didn’t eat breakfast, nor did she like the lunch that was served, so she had only eaten potato chips. Recalling a game card from the Elimi-Pain game, Letecia recalled that to stay healthy, she should eat nutritious foods. With that recollection she asked the art therapist if she would find something good for her to eat. (Wolf-Bordonaro, 2003)	Participants were encouraged to remember that ultimately they, not health-care professionals, had control over their lives and identities: “Just remember they don’t control who you are and what you do.. . whatever they say.” (Kirk et al., 2016) A parent stated, “(through the online network the ill child) has gotten to know (a health care provider) a lot better so he feels much freer, ...to go ask her for help.” (Nicholas et al., 2007) and they also realized that it was their own choice that would really help them recover. “I feel that then later on, maybe after the first month or so, it was more the choice that helped me, the choosing, am I going to go into the pits? No I’m not, I am going to go to the coach. It was at that stage of the process that I could feel more of an improvement coming on” (Reme et al., 2013) Catherine describes the changes she has observed in her daughter since returning home from camp: “Since going back to school – so camp, then it was school the next week – she realized that, and she knows that from camp as well,	Kirk et al., 2016, Nicholas et al., 2007, Reme et al., 2013, Stewart et al., 2011b/13, White, 2014, Wolf-Bordonaro, 2003	Asking for support: Improved relationships

	Theme: Empowerment	
	that she has to be an advocate for herself. That she’s the one that has to kind of put the foot down and say ‘this is why I need to stop and I’m going to stop”.(White, 2014)	

Theme: Empowerment				
Which bits of intervention relevant/how to engage	Therefore, they chose how much, when, and whether to pursue the myriad issues raised by living with childhood cancer. (Bluebond-Langer et al., 1991) The intervention was designed to create a supportive, structured environment that would give AYA opportunities to experience autonomy and independent decision making regarding the music, topics for the video, whether to involve family, friends, or care providers in the production process, and once completed, who would view it. (Docherty et al., 2013) For now, it is important that a variety of modalities be available for families to choose from, rather than expecting that one size fits all. (Gan et al., 2010) Additionally the "Challenge By Choice" (i.e., voluntary choices in personal participation and challenge) programming philosophy used by the camp supported inclusion of campers in all activities. For example, campers could decide to ride on a golf cart or walk across the camp, and they could choose how high to climb on the challenge course tower before riding the zip line back to the ground. One camper who became increasingly fatigued through the week decided to attend the closing According to a Teen Talk facilitator, the most effective locations for group dynamics and learning were those where individuals in the group could hang back and observe if they wished. It was important for campers to be able to hide their emotions within the larger group if they needed to, because "[i]t be real deep at Teen Talk" (Gillard	"The mentor manages to come into both worlds, the world of the adults and the world of my worries, he knows them, you can choose what to share with him and what not to share" (Barnetz et al., 2012)	Barnetz et al., 2012, Bluebond-Langer et al., 1991, Docherty et al., 2013, Gan et al., 2010, Gillard et al., 2011/13/16, Kirk et al., 2016 , Nicholas et al., 2007, Shrimpton et al., 2013, Stewart et al., 2013a	Accessibility: Child engages at level to meet own needs

	Theme: Empowerment
	et al., 2011) dance for only two songs before going back to rest in the health center. Compared to limitations faced at home such as avoiding germs and unsafe situations (Gillard et al., 2013) Sense of belonging refers to relationships that were cultivated and maintained throughout the camp session. Sense of belonging was the most identified theme, with 21 of the 24 campers commenting. Those 21 campers commented on sense of belonging 38 different times throughout their video recordings. Sense of belonging can be understood as the sensation of being connected and accepted by one's family, friends, and community (Kitchen, Williams, & Chowhan, 2012). This theme was most prevalent among campers with cancer and HIV/AIDS. (Gillard et al., 2016) Other individuals appeared to post messages only when they were experiencing a particular problem and did not engage in providing support to others. (Kirk et al., 2016) Age, developmental stage and personal interests appeared to have an impact on how the network was used by participating children. Reflecting typical developmental processes, younger children favored individual-oriented activities whereas older children and adolescents more frequently engaged in dyadic or group-based activities. Children under 10 years of age tended to engage in solitary activities such as playing

	Theme: Empowerment	
	online games more frequently than interacting or chatting with peers. For these younger children, the network was often seen as, in one parent’s words, a “distraction tool and entertainment.” (Nicholas et al., 2007) Both these video systems permitted a degree of selection by the patient as to either the content watched and/or the manner in which the system was used. (Shrimpton et al., 2013) Peer mentors believed that children enjoyed deciding whether information received was relevant to their needs.(Stewart et al., 2013a)	

	Theme: Empowerment		
What do I want outcome to be	It was also important for clinicians to learn ways to acknowledge other issues of concern that could be weaved into the BIFI-A intervention while still remaining focused on the goals of BIFI-A. (Gan et al., 2010) Finally, the focus on specific goals, and identifying barriers from reaching them, was also considered a helpful part of the treatment. (Reme et al., 2013) goal setting was adapted to focus on diabetes-related goals and a health diary was added as a weekly homework assignment to reinforce independent self-management; (Serlachius et al., 2012)		Gan et al., 2010, Reme et al., 2013, Serlachius et al., 2012
Control over environment	parents also felt it offered opportunity for the AYAs to exert control over the environment by making choices, creating something meaningful, and experiencing a sense of normalcy in the midst of an overwhelming focus on the illness and medical treatments: (Burns et al., 2010)) Pippa's mother noted how the production of the video provided a much-anticipated distraction from the seriousness and discomfort of daily radiotherapy, and was a vehicle for Pippa to express self-confidence and control in a frightening and life-threatening situation. (Shrimpton et al., 2013) The Environment Collage intervention provided occasions for subjects to make more than creative choices. It permitted the subjects to act out control over the hospital environment; subjects were given unique opportunities to give verbal orders to their		Burns et al., 2010, Shrimpton et al., 2013, Wolf-Bordonaro, 2003

Theme: Empowerment	
	caregivers, fellow patients, or family members. The opportunities for perceived control seemed to be the most important benefit of the environmental collage intervention. (Wolf Bordonaro)

Theme: Empowerment			
Sharing of control with interventionist/ parent (See code under mutuality tab)	Children reported that they were often ‘ignored’ in clinical consultations where they felt that ‘doctors’ talked more to their parents (Barlow et al., 1999) The mentors are part of the adolescent world and part of the adult world as well, and are not officials or figures of authority like teachers, doctors, or, in a different way, parents. But they still come from the adult world and even manage to live in it quite well. The ability of the adolescents to identify with their mentors has a positive and empowering effect.(Barnetz et al., 2012) Activities differentiated the LFP events from school experiences and promoted an atmosphere that was collaborative, encouraging and enjoyable. (Campbell et al., 2010) The resistance of the young people to obviously ‘psychological’ aspects of therapy, is prohibited without prior permission from the Society Experiences of CBT and psycho-education for CFS psychiatric settings, and psychological terms and labels also corresponds to literature concerning discrepancies between lay people and professionals regarding medically unexplained illness. Banks and Prior (2001) describe a ‘political struggle’ between CFS patients and health professionals to construct and frame the problem of CFS and its management. (Dennison et al., 2010) normal’’ life. Participants indicated that the activities were an important component of the programme. It was	“We did work out a strategy. It came from a birth plan. [The child] wrote out a needle plan, and she talked it through at home and worked it out with the psychotherapist here at the hospital. They did a 7-point plan. I think it read: ‘don’t tell me to be brave, I’ve been brave for ten years’ and ‘allow me to scream as much as I like. It helps me’, whereas people would tell her to calm down when she couldn’t. ‘Don’t tell me to turn away, I need to see what you’re doing’ and ‘I’ll tell you when I’m ready, don’t go until I’m ready’. It was just sort of a 7-point plan. She had it written on a card, and every time there was a new nurse or doctor she’d hand the card to them and they had to read it before going near her” (Ayres et al., 2011) The mentor manages to come into both worlds, the world of the adults and the world of my worries, he knows them, you can choose what to share with him and what not to share, (Barnetz et al., 2012) Campers discussed how most counselors treated them: “They're not over-protective. If something's wrong,	Ayres et al., 2011, Barlow et al., 1999, Barnetz et al., 2012, Campbell et al., 2010, Dennison et al., 2010, Gan et al., 2010, Gillard et al., 2013, Reme et al., 2013, Stewart et al., 2013a, White, 2014 , Wolf-Bordonaro, 2003, Wright et al., 2004

Theme: Empowerment		
	also important for clinicians to learn ways to acknowledge other issues of concern that could be weaved into the BIFI-A intervention while still remaining focused on the goals of BIFI-A. (Gan et al., 2010) There were different opinions regarding the therapists; some had only good experiences, while others found their therapist too controlling and not open for critical questions. (Reme et al., 2013) Mentors used children’s negative experiences to ask the group for better strategies to manage the situation (Stewart et al., 2013a) Additionally, caregivers would be able to accept that their children can take care of themselves, travel on their own, and engage in activities they normally would not want to participate in. (White, 2014) On two occasions during the intervention phase protocol, subjects invited third parties to participate in the Elimi-Pain Game. Subject 2 invited her young roommate; Subject 3 invited her brother. In both cases, the sessions were not interrupted by the participation of unexpected others. (Wolf-Bordonaro, 2003)	they'll be like ‘Well, do you want to do this or go here?’ They give you a choice.” (Gillard et al., 2013)

Theme: Empowerment				
Relinquishing power/Treating as equals/experts	Children reported that they were often 'ignored' in clinical consultations where they felt that 'doctors' talked more to their parents and also that health professionals were interested in the biological expression of JCA rather than the child as a person.(Barlow et al., 1999) The activities and games also differentiated the events from school experiences. The approach was a mixture of didactic teaching, questions were encouraged and participants were free to get snacks when they wished: I liked that you could just go and get a drink. It would have been like a school trip otherwise. They got to know us, not like teachers. (Philip, 14) (Campbell et al., 2010) The resistance of the young people to obviously 'psychological' aspects of therapy, psychiatric settings, and psychological terms and labels also corresponds to literature concerning discrepancies between lay people and professionals regarding medically unexplained illness. Banks and Prior (2001) describe a 'political struggle' between CFS patients and health professionals to construct and frame the problem of CFS and its management. (Dennison et al., 2010) challenges around engagement of adolescents, issues related to power and control, (Gan et al., 2010) The potential of online support groups to foster empowerment, potentially changing relationships with health-care professionals to ones based on partnership, has been noted in		Barlow et al., 1999, Campbell et al., 2010, Dennison et al., 2010, Gan et al., 2010, Kashikar-Zuck et al., 2016, Reme et al., 2013, Stewart et al., 2013a, White, 2014 , Wolf-Bordonaro, 2003, Wright et al., 2004	Empowerment (Move there?)

	Theme: Empowerment	
	previous research.58–60 (Kashikar-Zuck et al., 2016) There were different opinions regarding the therapists; some had only good experiences, while others found their therapist too controlling and not open for critical questions. (Reme et al., 2013) Peer-professional partnerships in support and education programs reduce differences in status and invite participation (Stewart et al., 2013a) Additionally, caregivers would be able to accept that their children can take care of themselves, travel on their own, and engage in activities they normally would not want to participate in. (White, 2014) The Environment Collage intervention provided occasions for subjects to make more than creative choices. It permitted the subjects to act out control over the hospital environment; subjects were given unique opportunities to give verbal orders to their caregivers, fellow patients, or family members. The opportunities for perceived control seemed to be the most important benefit of the environmental collage intervention. (Wolf-Bordonaro, 2003) it is important to Reme et al., 2013mber that successful implementation of the PSRM hinges on the basic assumptions and value orientation of the instructor…For a student to take on responsibilities and feel empowered in an adapted physical activity program, instructors must be willing to relinquish some of their control and share some of their power. This	

	Theme: Empowerment	
	subtle but yet critical shift in thinking may be the largest obstacle to successful implementation (Wright et al., 2004)	

Theme: Empowerment				
CYP taking responsibility for own care/take meds/homework/behaviour. Self-advocate	A variety of strategies to increase control were discussed, including play therapy, writing a letter, needle plans, and controlling the start of the procedure....The emphasis on control as a positive coping strategy is in contrast to research in other paediatric populations that suggests giving control to the child of when to start a needle procedure can increase distress...(Ayres et al., 2011) Parents expressed considerable frustration at the poor availability of psycho-educational interventions. The apparent scarcity of child-focused interventions led children to rely on parents for information.(Barlow et al., 1999) They reported on taking greater responsibility... belief that gives the mentees the strength to make the changes in their life required to achieve bio-psychosocial balance, from both the medical aspect (blood sugar balance) and from the quality of life aspect, and to live a full life with the disease.(Barnetz et al., 2012) sense of independence and readiness to play a bigger part in their own health care.(Campbell et al., 2010) When ChIPS first started, the co-ordinator recruited young people she thought might become part of the reference group and peer leaders themselves as the first cohort to participate in the program. (Lewis et al., 2016) Parents who participated in focus groups 1 and 2 and two of the five coordinators identified that young people could explore strategies for independence during the Introductory Program, often shown in one of two ways. According to	“It came from a lack of control as children are forced into it. They are forced and have no option. The people who love you the most, your mother is holding you down . . . I think being constrained, being held down by a number of people made it worse. It was the whole sorry process” (Ayres et al., 2011) Children were adamant that they should not be shielded from the more negative aspects of JCA and its treatment. As one child said: I” want to know everything.” (Barlow et al., 1999) ‘‘Cause out of breath after doing a lot of walking around. This made me want to practice’’ ‘‘It’s been going good. Usually do it in my room. I do it whenever I am wheezing.’’ ‘Nothing has gotten in the way, I just remember, no one reminds me’’ (Bignall et al., 2015) An uncle stated, “She used to have a little attitude before, but now she can deal with people a little better. . .She has a little more respect. . .She’s more responsible.” (Fair et al., 2012) As one adolescent reported, ‘‘It made me realize to keep checking	Ayres et al., 2011, Barlow et al., 1999, Barnetz et al., 2012, Bignall et al., 2015, Campbell et al., 2010, Fair et al., 2012, Jaser et al., 2014, Kashikar-Zuck et al., 2016, Kirk et al., 2016, Lewis et al., 2016, Muskat et al., 2016, Nicholas et al., 2007, Reme et al., 2013, Serlachius et al., 2012, Sibinga et al., 2011, Stewart et al., 2013a, White, 2014, Wright et al., 2004, Wolf-Bordonaro, 2003	Managing Myself, Info/Emotional Support

Theme: Empowerment			
	parents in one focus group, one way was to prioritise their time in order to ensure their availability to attend ChIPS. Mother: … because [my daughter] now is in Year 11, maybe sometimes got an assignment to do, and I say 'If you've got an assignment, you don't go [to ChIPS]—if you are not so busy you can go there'. (FG4) According to both former ChIPS co-ordinators, the other was to make explicit plans to achieve particular tasks,(Lewis et al., 2016) The network educated and contributed to ongoing and important processes of self-care and social support. (Nicholas et al., 2007) More than half of adolescents reported that they used PA exercises during the course of the study (n = 11/20 interviewed), primarily when they were upset, stressed, or sad or when checking their blood glucose level. (Jaser et al., 2014) and they also realized that it was their own choice that would really help them recover...A possible sick role has been suggested as a contributory maintaining factor for CFS in some people as illustrated in the case history ofYP7, and indeed secondary gains from CFS have been shown to reduce the likelihood of improvement following psychological therapy (Bentall et al., 2002). We may therefore conclude that a process in which clients choose to put themselves in the role of their own 'coach', providing encouragement to themselves, may counteract the 'sick role' identity. This may be done by moving them	(blood glucose) in the back of my mind.'' (Jaser et al., 2014) The mini-relaxations I will do during the day...if I get tensed up doing something. I will stop and do a mini-relaxation.(Kashikar-Zuck et al., 2016) later on, maybe after the first month or so, it was more the choice that helped me, the choosing, am I going to go into the pits? No I'm not, I am going to go to the coach. It was at that stage of the process that I could feel more of an improvement coming on' (YP6). (Reme et al., 2013) Catherine describes the changes she has observed in her daughter since returning home from camp: "Since going back to school – so camp, then it was school the next week – she realized that, and she knows that from camp as well, that she has to be an advocate for herself. That she's the one that has to kind of put the foot down and say 'this is why I need to stop and I'm going to stop'." (White, 2014)	

	Theme: Empowerment	
	towards viewing themselves as being active and positive in how they manage their illness. Indeed, participants commented on the helpfulness of having an active choice in how to respond to distress so as to assist recovery (Reme et al., 2013) In three of the groups, adolescents expressed the desire to be more independent in their diabetes management, and wanted the programme to motivate them to take better care of themselves.(Serlachius et al., 2012) Information Support. The children gave concrete examples of information support including learning about triggers such as the benefits of allergen avoidance and new strategies such as placing asthma medication on night tables so “I don’t forget”...Many children were used to their parents managing their situations and thinking about how they would manage responsibility was a new experience.(Stewart et al., 2013a) as many participants gave in-depth descriptions of how and when they use the MBSR techniques and the resultant effect.(Sibinga et al., 2011) Lastly, participants suggested that camp taught their children to advocate for themselves when being physically active.All caregivers described positive changes in their child’s ability to be self-reliant. Participants were happy and proud that their children were maturing and wanting to take on more responsibilities. (White, 2014) The researcher had an interesting opportunity to observe the assimilation of new	

	Theme: Empowerment	
	information by one of the subjects. As reported in the Appendix K, the researcher escorted Subject 1 to her room following the Elimi-Pain Game. Upon reaching her room, Subject 1 stated she felt dizzy and required help to get into bed. The art therapist asked if she had eaten that day. Subject 1 explained that she didn’t eat breakfast, nor did she like the lunch that was served, so she had only eaten potato chips. Recalling a game card from the Elimi-Pain game, Letecia recalled that to stay healthy, she should eat nutritious foods. With that recollection she asked the art therapist if she would find something good for her to eat. (Wolf-Bordonaro, 2003) For a student to take on responsibilities and feel empowered in an adapted physical activity program, instructors must be willing to relinquish some of their control and share some of their power. This subtle but yet critical shift in thinking may be the largest obstacle to successful implementation (Wright et al., 2004)	

Theme: Empowerment			
Activities: mastery/ achievement	Self-efficacy may offer a useful starting point for development of equivalent initiatives targeting children and their parents. The basic tenets of self-efficacy theory suggest that providing participants with mastery experience, role modelling, credible sources of information and the skills to re-interpret physiological state in a positive manner will enhance self-efficacy beliefs(Barlow et al., 1999) Finally, the feelings of joy and happiness and experiencing encouragement from the BOC Program might help the child gain awareness and resolution in the midst of a challenging life event to strengthen outcomes of resilience including confidence/mastery and self-esteem.(Baruch, 2012) Two students (14.3%) asked for additional materials so that they could teach their family members.(Bignall et al., 2015) Initial uncertainty or reservation was replaced by a sense of pride, competence, and mastery.(Burns et al., 2010) and reported feeling a sense of competence and personal fulfilment when achieving new skills in activities such as archery or canoeing....Several campers reflected that participation in the talent show allowed them to overcome anxiety and develop confidence. (Desai et al., 2014) Campers learned how to do new things, such as shoot paintballs and arrows. (Gillard et al., 2011) At camp, youth gained confidence by persevering through challenges, which	Parents also mentioned the benefits of play therapy in managing needle-related distress. “Children practice injecting into an orange. It took a couple of sessions, but that’s how we got round it in the end (P9:Mother). (Ayres et al., 2011)‘‘ I thought [the techniques] were helpful and something I would want to teach my sister’’ (Bignall et al., 2015) One of the children replied, ‘‘I’ve never really done archery before, but it’s like ... I didn’t know I could. When I first fired and stuff I missed a lot and didn’t think I could hit it at all, but I did!’’ (Bultas et al., 2015) “It just happened that she was doing this with you at one of her lowest points, and so I guess the change in it, and the interesting thing that came out of it, is that she could actually do it against all odds.” (Father, daughter, 21 years old Burns et al., 2010) Another camp program that affected the camper study participants included the ropes course and zip line. One camper said, “I have to say my favorite memory from camp would	Ayres et al., 2011, Barlow et al., 1999, Baruch, 2012, Bignall et al., 2015, Bultas et al., 2015, Burns et al., 2010, Desai et al., 2014, Gillard et al., 2011/13/16, Kashikar-Zuck et al., 2016, Lewis et al., 2016, Moola et al., 2015, Nicholas et al., 2007, O’Callaghan et al., 2013, Shrimpton et al., 2013, Tiemans et al., 2007, White, 2014/16,

	Theme: Empowerment	
	participants and staff believed could carry over to other situations that required successful coping skills, such as enduring painful cancer treatments (Gillard et al., 2013) According to one ChIPS co-ordinator, camp attendance, rather than the Introductory Program, had more potential to build resilience in ChIPS members by creating opportunities for them to face their fears and work through strategies to conquer them. (Lewis et al., 2016) such as the importance of providing sick children with fun, independence, mastery experiences, friendship and a sense of normalisation in an outdoor environment (Moola et al., 2015) SBW was described as fostering mastery and coping. (Nicholas et al., 2007) Music can provide security, reassurance, relief from boredom, and opportunities for choice and control, without requiring concentrated effort or verbal comprehension: communication occurs through meanings associated with melodic inflexions and timbres.(O'Callaghan) As part of the rigorous program within the camp, participants realized success in mastering difficult tasks.(Tiemans et al., 2007) I think that she came back with more an idea that she could have more freedom. She came back, she’s like ‘why do I have to ask you now, I’ve done this on my own [at camp]’ … But I think it [camp] gave her just that little bit more of an independence to know that she can do these things, which is good. I mean she realizes	probably be climbing the tower. It was an incredible experience. When I got to the top I felt like I accomplished, you know, what I wanted to do. The zip line was probably the best part also.” (Gillard et al., 2016) “For some of these people, they're very sheltered and their parents don't let them do anything, and they're climbing rockwalls and going down zip lines, and the fact is that they're overcoming their fears and obstacles.” (Gillard et al., 2013) “then at the end you got to put them all together and see how much better you had gotten.” (Kashikar-Zuck et al., 2016) “I was always like super nervous because my family has always been so cautious of what I do, that I always, I got that now too. I’m anxious of things I don’t know. Camp kinda made me realize that ‘I can – I’m underestimating myself in some situations, that I can do more than I thought I could and I really push myself more. It is just the fact that I could do like extreme et al., 2013 things at camp, without having to worry about anything. I was the first one to do

Theme: Empowerment			
	that she can go to camp and be on her own and she does The majority of caregivers perceived that Camp Oki would allow their children to get a break from their families and realize what they can accomplish without their family or friends present not need us around to remind her to do all the things that need to be done. So I think psychologically she grew up while she was away. (White, 2014)	the rock climbing out of my group and I've never done it before. And, the water skiing – I've never done and it's just all these things I wouldn't imagine doing with my health because I'd be too scared. I had nothing to worry about at camp, so it was really fun." (Moola et al., 2015) "It was unbelievable … Lucy's whole manner changed. She had been very withdrawn and difficult to talk to—we had to almost pull her kicking and screaming into the radiation treatment room. (She then became) a little girl who took control of the situation for herself because she saw what she was doing … so we went from a little girl that we were bribing and carrying to the car, at home my husband had to carry her into the car kicking and screaming and hold her down and put her in the car every day … a little girl who wouldn't look at me in the face, who became very withdrawn, sad and upset to a little girl, to you won't believe it— she used to skip down to the radiation room when it was her turn and would tell us what she was going to do."(Shrimpton et al., 2013)	

Theme: Empowerment		
	“I was like, ‘wow’ you know, hard things that you overcome, you are, kind of feel that you are such a good person.” (Tiemans et al., 2007) “Oh it will be a wonderful feeling knowing that he has accomplished things that we never thought he would be able to accomplish either. So it would be a great feeling for our family that, ‘hey you know what, now we know that this is something he enjoys, we should get him involved in it or look where else we can do it” (White et al., 2016)	

Theme: Empowerment			
Tailored structuring: encouraging recognition	Nearly all participants reported increased confidence and self-efficacy as a result of the program, having a sense of pride in their accomplishment, and being happier. The majority also reported noticing a progressive increase in their strength, staining, and physical functioning (Kashikar-Zuck et al., 2016) This understanding of courage, and the process of helping the child become aware of their courage and mastery of a difficult situation is especially relevant when considering the more distal outcomes of resilience (Haase, 1987; Pearlin & Schooler, 1987). The fact that fewer children describe the BOC Program as a symbol of accomplishment might be directly related to where they are in their treatment journey, and the opportunities provided for them to either interact with others for social comparison to help them develop confidence or mastery in the midst of dealing with the very difficult experience of receiving treatment for cancer. (Baruch, 2012) Based on the findings of this study, the following includes several recommendations for camps to consider for strategic planning efforts to optimize supportive developmental experiences for youth with cancer. First, camp should provide structured and facilitated activities that encourage campers to reflect on their challenges and successes in camp and in life. (Gillard et al., 2013)	“it feels different , knowing that I have something to Reme et al., 2013mber;” child (004) “looking back and already seeing how much I’ve gone through;” child (005) the BOC Program “makes me remember;” and child (006) “helps me remember what happened.” (Baruch, 2012) “calendar of the last 9 months;” and parent (SS) who said “when she is old enough it’s a reminder for her...something that she’ll always have.” “then at the end you got to put them all together and see how much better you had gotten.” (Kashikar-Zuck et al., 2016)	Baruch, 2012, Kashikar-Zuck et al., 2016, Gillard et al., 2013

Theme: Empowerment			
Transfer of empowerment outside session	Adolescents unanimously reported increased confidence levels that were evident within the confines of the group, as well as in their everyday interactions. (Fair et al., 2012) This group made me more confident...the increased confidence and sense of strength. (Kashikar-Zuck et al., 2016)I know what I can do and if I feel like there's pain or I feel like I shouldn't be doing this, I will let the teacher know and I will stop. (Moola et al., 2015) In mentors' views, this support group helped children to deal with social challenges of asthma or allergies, such as confidently explaining their condition to others. (Stewart et al., 2013a) The majority of caregivers perceived that the camp experience would instill independence in their children once they returned home. These caregivers anticipated that their children would learn how to be away from their family, learn to take care of themselves without parental assistance, and ultimately gain independence in activities of daily living. (White, 2014) As a result of pleasurable camp experiences and children's accomplishments, parents used camp as a 'reinforcing tool' to reconnect back to mastery camp experiences. (White et al., 2016) The authors identified positive outcomes associated with the effects of a sense of control, and presented themes for further development. They also revealed a particularly useful application of perception of LOC which parallels	"I didn't think I could do all the things I can do now at all." (Kashikar-Zuck et al., 2016)	Fair et al., 2012, Kashikar-Zuck et al., 2016, Moola et al., 2015, Stewart et al., 2013a, White, 2014/16 , Wolf-Bordonaro, 2003

	Theme: Empowerment	
	the data on Subject 2. The authors argued that ameliorative effects of control are residual, extending beyond the immediate situation over which an individual perceives control. (Wolf-Bordonaro, 2003)	

Theme: Empowerment				
Having voices heard	Children reported that they felt unable to ask questions in clinical settings. There was consensus among the children that they were ‘the experts’ and they felt that they should be consulted in the development of psychoeducational interventions for the future. The strength with which children expressed these views was very clearly observable to the focus group moderators. As one child said: You’ve really got to ask people like us what we want...otherwise you’ve just got a load of people who think they know about arthritis. It doesn’t work... It’s not doing anything for anyone. (Barlow et al., 1999) The children are actively engaging with their treatment experience and using the BOC Program to visually tell others. All stories are meant to be told, and the BOC Program is afforded the participating children with a visual storytelling method. (Baruch, 2012) Subthemes included honoring and valuing AYA privacy needs related to DVD creation and respect for AYA decisions regarding who would view the DVD. (Docherty et al., 2013) They were more empowered and they found that voice, that ‘I have something to say, I’m not invisible, and that I matter.”’ (Fair et al., 2012) Feeling successful was linked to feelings of choice and self-expression, and these feelings emanated from a social structure that provided connections to peers (i.e., fellow campers), role models (i.e., former campers serving as counselors), and (Gillard et al., 2013)	An interesting management technique already mentioned was a needle plan. The child’s parent described how the needle plan was developed and used: “We did work out a strategy. It came from a birth plan. [The child] wrote out a needle plan, and she talked it through at home and worked it out with the psychotherapist here at the hospital. They did a 7-point plan. I think it read: ‘don’t tell me to be brave, I’ve been brave for ten years’ and ‘allow me to scream as much as I like. It helps me’, whereas people would tell her to calm down when she couldn’t. ‘Don’t tell me to turn away, I need to see what you’re doing’ and ‘I’ll tell you when I’m ready, don’t go until I’m ready’. It was just sort of a 7-point plan. She had it written on a card, and every time there was a new nurse or doctor she’d hand the card to them and they had to read it before going near her” (P14:Mother). (Ayres et al., 2011) Clinicians share that the children “want to be able to tell their story,” and through the BOC Program they observe how “even the quiet kids start to talk,”	Ayres et al., 2011, Barlow et al., 1999, Baruch, 2012, Docherty et al., 2013, Fair et al., 2012, Gillard et al., 2013, Muskat et al., 2016, Wright et al., 2004, Wolf-Bordonaro, 2003	therpeutic relationships/Self-expression Link to self-esteem.(I matter)

Theme: Empowerment			
	Participation in a mutual aid group can lead to feelings of empowerment and self-advocacy, which are extreme et al., 2013ly important for children and teens with HIV, who may regularly face stigma and discriminatory views of others. (Muskat et al., 2016) The third PSRM responsibility, self-direction, includes making group decisions, and individual choices. Some participants like Jerry and Brandon were quite shy when they entered the program. Toward the beginning they were reluctant to make choices and contribute their ideas in group discussions. By the end of the program both had become more comfortable about making choices and expressing their opinions. (Wright et al., 2004) The Environment Collage intervention provided occasions for subjects to make more than creative choices. It permitted the subjects to act out control over the hospital environment; subjects were given unique opportunities to give verbal orders to their caregivers, fellow patients, or family members. The opportunities for perceived control seemed to be the most important benefit of the environmental collage intervention. (Wolf-Bordonaro, 2003)	(Baruch, 2012) the confines of the group, as well as in their everyday interactions. For example, one 15-year old male explained, “I got to speak my mind and didn’t have to hold anything in.” A 15-year old female stated “We could all talk about things. And I wasn’t really scared to write or anything. I just did it.” (Fair et al., 2012)	

Theme: Empowerment			
Voices heard within wider community	Some participants also emphasized the importance of building self-esteem to help them become leaders in their communities rather than followers. (Hosek et al., 2012) Participation in a mutual-aid group can lead to feelings of empowerment and self-advocacy, which are extreme et al., 2013ly important for children and teens with HIV, who may regularly face stigma and discriminatory views of others. (Muskat et al., 2016)	“R: How is that different than from before the program? P: I never talked about it, just kept quiet. R: You talk a lot more now? P: Yeah, I do. I want them to understand what I’m going through and also to support myself, support us if we have any problems and stuff like that. At first, I didn’t feel comfortable talking to anybody because I’m scared and I feel like they’ll only lecture and not understand. But now that I’m talking to different families, different people, a support group, so I talk more, and it makes me appreciate what I have.” (Brodeur, 2005) “I want people to know that I don’t think you should treat people differently just because they have HIV or AIDS.” (p. 15) “I’ll tell people that they shouldn’t be mean to the people who have HIV. I think that people should not be afraid of the people who have HIV. I think that the ones who don’t have HIV should have a friend who has HIV or just be friends with everybody. When people pick on people who have HIV, they make the person feel really sad or mad. I want to	Brodeur, 2005, Fair et al., 2012, Hosek et al., 2012, Muskat et al., 2016, White, 2014

Theme: Empowerment
tell whoever is reading this not to be like that, because the ones who have HIV or AIDS are normal people, just like you.” (p. 26) (Fair et al., 2012) “It has influenced me to become more active in AIDS and HIV in teaching others about AIDS and HIV, becoming more open about my disease because I do live in a community where I have certain people around me who will not judge me for my disease. So it has taught me to become more open about my disease and not to be in the shadows.” (Fair et al., 2012) “I mean, just teach them about decision making. It ain’t necessarily wrong crowd, right crowd, but if you become your own individual and you learn how to be a leader and not a follower, you can hang with people who doing what they doing.” (Hosek et al., 2012) Catherine describes the changes she has observed in her daughter since returning home from camp: “Since going back to school – so camp, then it was school the next week – she realized that, and she knows that from camp as well, that she has to be an advocate for herself. That she’s the one

Theme: Empowerment
that has to kind of put the foot down and say ‘this is why I need to stop and I’m going to stop’.” (White, 2014)

Theme: Self-Esteem				
Idea for further interpretation/ Third Order Construct	Second Order Construct	Quote	Papers contributing	Acknowledgement of overlap
Reinforce belief in ability to manage condition/emotions and negative responses from other people	This example was far from unique in our evaluative study, with almost all interviewees speaking of the 'empowering' and 'self-reinforcing' benefits of the programme and how this contributed to their child's adjustment, coping and compliance with RT. (Shrimpton et al., 2013) Children thought that affirmation support including assurance that others experience the same problems was as important as emotional support. Children enjoyed other children's and peer mentors' encouragement that they were doing the right things to manage their condition and could handle negative reactions from other people. (Stewart et al., 2013a)	"I was very encouraged and I also felt liberated when he shared that 'I feel more brave mommy because I don't feel like an outcast because I know they're other kids like me'. That really made a difference for me. I don't worry – I mean I will always worry about his health but I'm not worrying about how he feels about himself." (White, 2014)	Shrimpton et al., 2013, Stewart et al., 2013a, White, 2014	social support

	Theme: Self-Esteem		
Value opportunity to recognize positive things about themselves		“Did you learn anything about your family that you didn’t know before the program? P: I didn’t realize that they thought I was delightful. When we made the rocks we had to tell the personality. I didn’t realize they thought I was like that. P: How’d that make you feel? R: Good. I made me feel really good.” (Brodeur, 2005) In addition, participants reported that programs should have opportunities for young women to learn something positive about themselves, as one young woman stated: ‘‘Tell them something about themselves that they may not see, but what you see in them.’’ (Hosek et al., 2012) “I liked how we played ‘weaving the web’ and we saw what we thought of each other” (Gan et al., 2010) Adolescents also reported that self-affirmations were helpful. One adolescent stated that when he was upset, he ‘‘thought about what I was proud of or what made me happy, which helped me to calm down and be happy again.’’ (Jaser et al., 2014) To know that I was doing it right felt really good. (Kashikar-Zuck et	Brodeur, 2005, Gan et al., 2010, Hosek et al., 2012, Jaser et al., 2014, Kashikar-Zuck et al., 2016, Tiemans et al., 2007

Theme: Self-Esteem		
	al., 2016) The element of support [was appreciated]. . . . “Everyone had tons of encouragement and “oh, you can do it.””(Tiemans et al., 2007)	

Theme: Self-Esteem				
Role of positive recognition /affirmation in self-esteem or impact on mood	The fact that there is a difference between the stakeholders who describe the BOC Program as an accomplishment is an interesting finding. There often is an interpersonal assignment of courage by others before it is fully realized or experienced by the one facing a difficult situation requiring courage…In other words, the clinicians and parents in this study view the children as having courage and deserving of honor, recognition and accomplishment. The BOC Program becomes the way to provide the child with a “visible representation of their accomplishments,” or to help the child “understand her courage, how special she is. (Baruch, 2012) There seemed to be a turnaround for the parents, where they went from viewing their child as suffering, to seeing their AYAs as having positive, normal characteristics and having amazing multiple strengths. (Burns et al., 2010) Receiving positive, encouraging and normalising messages about their sexuality and sexual behaviour is important in order that positive young people do not grow up with negative feelings about themselves, sex and sexuality (Campbell et al., 2010) Travers and Lawler (2008) describe a ‘violated’, ‘struggling self’ whose suffering is largely unacknowledged by others and a protective ‘guardianship’ response concerned with self defense, and assuming the burden of proof. (Dennison et al., 2010) The participants voiced that they enjoyed getting to know the counsellors, felt	“It made me happier, seeing her encourages me, she’s like me and she’s okay, she works… It’s like talking with myself, but it’s not me.” (Barnetz et al., 2012) “Did you learn anything about your family that you didn’t know before the program? P: I didn’t realize that they thought I was delightful. When we made the rocks we had to tell the personality. I didn’t realize they thought I was like that. P: How’d that make you feel? R: Good. I made me feel really good. “(Brodeur, 2005) Participants consistently approved that being recognized for their special talents at the closing event felt “good . . . cause it makes you know that you have done something cool.’ “(Desai et al., 2014) “I liked how we played ‘weaving the web’ and we saw what we thought of each other” (Gan et al., 2010) “Some of the girls will get off [the bus] wearing wigs. And they see other kids. They're not around other children with cancer, right? Maybe in clinic, but that's very, very different. And they've been made fun of in school, and people	Barnetz et al., 2012, Baruch, 2012, Brodeur, 2005, Burns et al., 2010, Campbell et al., 2010, Dennison et al., 2010, Desai et al., 2014, Gan et al., 2010, Gillard et al., 2013, Kashikar-Zuck et al., 2016, Kirk et al., 2016, Nicholas et al., 2007, Shrimpton et al., 2013, Stewart et al., 2013a, Tiemans et al., 2007 White, 2014, Whittemore et al. 2010, Wright et al., 2004	Adopting into daily life

Theme: Self-Esteem		
	comfortable with them, enjoyed their playfulness, and valued the assistance, supervision, and positive regard they received from them (Desai et al., 2014) Adolescents also reported that self-affirmations were helpful. One adolescent stated that when he was upset, he ‘‘thought about what I was proud of or what made me happy, which helped me to calm down and be happy again.’’ (Jaser et al., 2014) Nearly all participants reported increased confidence and self-efficacy as a result of the program, having a sense of pride in their accomplishment, and being happier. as well as boosting feelings of self-esteem and confidence through postings emphasizing the inherent strengths of people with CF....Woven through these postings were messages which appeared to aim at building the young person’s confidence and self-esteem (Kirk et al., 2016) This example was far from unique in our evaluative study, with almost all interviewees speaking of the ‘empowering’ and ‘self-reinforcing’ benefits of the programme and how this contributed to their child’s adjustment, coping and compliance with RT. (Shrimpton et al., 2013) As part of the rigorous program within the camp, participants realized success in mastering difficult tasks. Extensive recognition and encouragement were provided.(Tiemans et al., 2007) Gary’s mother also saw improvements in this area. She noted that he was proud of what he	just stare at them in public. And they get here and they see other children wearing do-rags, but at the pool they see the bald kids…And being a kid again, and feeling that acceptance I think is tremendous for their self-esteem.” (Gillard et al., 2013) “Calming statements and I would be like...you can do this...you will feel better once you are done... I don't feel better physically, but I feel better mentally, because I knowl was active that day.” (Kashikar-Zuck et al., 2016) “I think it encouraged (the ill adolescent) ...to know that he had the ability to ‘do.’ I think it really boosted his confidence, knowing that he had something to offer other kids, and that someone saw that while he was on the computer. I think that it made him happy to think that he might be able to give to somebody. So I would say that it really gave him a boost in his confidence, which is a real important thing.” (Nicholas et al., 2007) “Watching the video at home also provided ‘more positive reinforcement of how wonderful she was and how brave’ and contributed further to her

Theme: Self-Esteem			
	was learning. She said he would often “show off” his techniques at home. (Wright et al., 2004)	willingness to receive treatment.” (Shrimpton et al., 2013) Similarly, Julie explains how her daughter engaging in new activities would help improve her self-esteem: 55 “I think it’s going to give her such a boost in what she can accomplish. It’s going to give her a look at what she can do. Instead of always been told what you can’t do. She’s going somewhere where she can do everything there – that’s a huge deal” (White, 2014) “This is really cool. I love the characters. I want to name them. I like that you can see the (insulin) pumps” (Whittemore et al. 2010)	

Theme: Self-Esteem			
Opportunities to tell story/ communicate experiences and receive positive feedback from others.	The BOC Program is viewed by the parents and clinicians, more than the children, as a way to visibly show what the child has achieved during treatment. Words used frequently by stakeholders, such as “reward”, “honor,” and “bravery” were condensed to form this emerging category. (Baruch, 2012) There seemed to be a turnaround for the parents, where they went from viewing their child as suffering, to seeing their AYAs as having positive, normal characteristics and having amazing multiple strengths. (Burns et al., 2010) Watching the video at home also provided ‘more positive reinforcement of how wonderful she was and how brave’ and contributed further to her willingness to receive treatment....This example was far from unique in our evaluative study, with almost all interviewees speaking of the ‘empowering’ and ‘self-reinforcing’ benefits of the programme and how this contributed to their child’s adjustment, coping and compliance with RT. (Shrimpton et al., 2013)	Parent (J) stated that the beads in the Program show “his bravery…signify the strength he’s had,” (Baruch, 2012)	Baruch, 2012, Burns et al., 2010, Shrimpton et al., 2013
Structuring/ tailoring provides opportunity to reflect	The majority of participants also enjoyed the structure of the program, progressively learning new exercises every 2 weeks before ultimately creating the full functional movement, and monitoring their own progress. (Kashikar-Zuck et al., 2016)	I am glad that I went through it... now I can look back...at how far I have come... (Kashikar-Zuck et al., 2016)	Kashikar-Zuck et al., 2016,

Theme: Self-Esteem				
Self of mastery leading to self-esteem/improved mood	The majority of participants also enjoyed the structure of the program, progressively learning new exercises every 2 weeks before ultimately creating the full functional movement, and monitoring their own progress.... Nearly all participants reported increased confidence and self-efficacy as a result of the program, having a sense of pride in their accomplishment, and being happier. (Kashikar-Zuck et al., 2016) Identified outcomes of mastery and coping appeared to coincide with increased self-esteem.(Nicholas et al., 2007) As part of the rigorous program within the camp, participants realized success in mastering difficult tasks. (Tiemans et al., 2007)Gary's mother also saw improvements in this area. She noted that he was proud of what he was learning. She said he would often "show off" his techniques at home. (Wright et al., 2004)	Another camp program that affected the camper study participants included the ropes course and zip line. One camper said, "I have to say my favorite memory from camp would probably be climbing the tower. It was an incredible experience. When I got to the top I felt like I accomplished, you know, what I wanted to do. The zip line was probably the best part also." (Gillard et al., 2016) As an example of perceived benefits of self-mastery, one adolescent who had been terrified of heights climbed to the top of the high ropes. She later reported, "I was like, 'wow' you know, hard things that you overcome, you are, kind of feel that you are such a good person." (Tiemans et al., 2007)	Gillard et al., 2016, Kashikar-Zuck et al., 2016, Nicholas et al., 2007, Tiemans et al., 2007, Wright et al., 2004	Empowerment

Theme: Self-Esteem				
Focus on what CYP can do		“Especially because she lost all her hair, she wasn’t feeling like she was very attractive but people would enjoy her tape. So when you lose all else, to have something that you’re really proud of.” (Burns et al., 2010) Participants consistently approved that being recognized for their special talents at the closing event felt “good . . . cause it makes you know that you have done something cool.”(Desai et al., 2014) “It can be up to you how. The first thing I can say, like I should say, realize what is it. Like when you know WHAT is it, then accept yourself first before you want other people to accept you. Then once you just tell yourself, okay, this is what I have, and this is me, and there’s nothing wrong about me. It’s just the HIV, and if you think HIV is living you, and living with it, so that’s another problem. You don’t have to just, so okay, I have HIV, I cannot go to school, I cannot do this, I cannot do that. You can still be a doctor while you’re HIV positive. You can still do everything. So that’s the thing, I mean, I think you have to accept yourself.” (Hosek et al., 2012)	Burns et al., 2010, Desai et al., 2014, Hosek et al., 2012, White, 2014, Wright et al., 2004,	Empowerment

Theme: Self-Esteem
Similarly, Julie explains how her daughter engaging in new activities would help improve her self-esteem: “I think it’s going to give her such a boost in what she can accomplish. It’s going to give her a look at what she can do. Instead of always been told what you can’t do. She’s going somewhere where she can do everything there – that’s a huge deal” (White, 2014) Omar’s mother explained the significance that this special activity had for her son. She said, “I don’t want his sister or brother to be in a private karate class. This has really helped him a lot. Even during the week when they do things that he can’t do, we mention the karate thing. I tell him that he does karate and they don’t.” (Wright et al., 2004)

Theme: Self-Esteem				
Opportunity to reflect on what been through/ understand self	Interestingly, findings from the data collected from children do not support this emerging category as strongly as the other three categories. Only two of the six children interviewed used words to describe the BOC Program as a symbol of accomplishment. Child (004) did say that the BOC Program was "an accomplishment" and he uses his beads to show to family and friends to show what he has gone through and that he has this and they don't. (Baruch, 2012) Based on the findings of this study, the following includes several recommendations for camps to consider for strategic planning efforts to optimize supportive developmental experiences for youth with cancer. First, camp should provide structured and facilitated activities that encourage campers to reflect on their challenges and successes in camp and in life. (Gillard et al., 2013) For seven participants, self-awareness was enhanced through social comparison. (Stewart et al., 2011b)	"it feels good...it can show happiness;" and child (002) "when I'm feeling sad they make me happy;" and child (004) "makes me happy, brings a smile. (Baruch, 2012) For seven participants, self-awareness was enhanced through social comparison. "It helped me understand a bit more about myself and my limitations and my goals" (Stewart et al., 2011b)	Baruch, 2012, Gillard et al., 2013, Stewart et al., 2011b	Delivery of intervention: Keeping it going

		Theme: Self-Esteem		
Mementos	All stakeholders described how the BOC Program is used as a “reminder” to help Reme et al., 2013mber the cancer treatment experience. (Baruch, 2012) Most campers discussed in detail how they reflected on and looked forward to opportunities for reprieve and recreation all year. One camper told another camper, “This is the most fun I have all year.” The activities of anticipation and reflection were supported through camp mementos such as a memory book, diplomas, certificates, awards, and gifts from counselors. (Gillard et al., 2011) At camp, it was evident that participants (campers and counselors) felt connected to a phenomenon with a past and a future. For example, a camp volunteer created a DVD film of the previous year that camp administrators and volunteers gave to potential and past participants, and showed on the first night of camp. (Gillard et al., 2013) One camper stated, “If I could take anything with me from camp I would take the bandanas … each one represents our [unit cabin]… and I feel like each color represents what we did that session and it's just very special.” The color on his bandana helped represent what camp meant to him more so than the ropes course, theater, or dining hall. (Gillard et al., 2016)	“it feels different , knowing that I have something to remember;” child (004) “looking back and already seeing how much I’ve gone through;” child (005) the BOC Program “makes me remember;” and child (006) “helps me remember what happened.” (Baruch, 2012)	Baruch, 2012, Gillard et al., 2011/13/16	Overlaps with ?

Theme: Availability

Theme: Availability				
Idea for further interpretation/ Third Order Construct	Second Order Construct	Quote	Papers contributing	Acknowledgement of overlap
Recognition of (MH) need	Parents expressed immense frustration and anger at the number of social barriers that thwarted attempts to achieve these goals. They felt that their children met with discrimination and criticized both Health and Educational services for a perceived lack of support and assistance. Children at the milder end of the disease spectrum appeared particularly vulnerable in this respect. When JCA was less visible, children and their families reported a lack of both institutional and personal support. ...A dominant theme across all focus groups concerned the failure of current psycho-educational interventions to address the wider aspects of JCA (e.g. psychosocial impact). (Barlow et al., 1999) On many occasions when professionals encounter such adolescents, who actually ignore numerous aspects of their disease, they attempt to provide them with knowledge on the implications of their actions, but the threatening knowledge might have the opposite effect: it will only increase the anxiety that caused the adolescent to ignore the disease in the first place. This line of thinking echoes the conclusion of Hood et al. (2010) whereby focusing on juvenile diabetic adherence behavior and neglecting emotional and	"They really don't understand the problems you have at home... The doctors see them for half an hour...and examine the joints...but, it doesn't just affect their joints. It affects them mentally and that's what we have to put up with." (Barlow et al., 1999)	Barlow et al., 1999, Barnetz et al., 2012, Campbell et al., 2010	

	Theme: Availability	
	social factors is unlikely to have a positive impact. (Barnetz et al., 2012) Further work may need to be developed within the family clinic to identify and support families who may be struggling (Campbell et al., 2010)	

Theme: Availability			
Limited availability: transition=hard!	Children and parents felt that there was an enormous gap between their need for information and the information they actually received. In general, health professionals, voluntary groups and parent oriented leaflets were cited as their main sources...Parents appeared to be the main recipients of educational interventions, the emphasis being on the provision of actual information regarding disease process (e.g. disease pathology, incidence of disease) and hospital attendance as either in-patients or out-patients....Clearly, greater availability of a range of educational materials and group or individual interventions combined with ease of access will be of paramount importance in the future (Barlow et al., 1999) As the BIFI-A is the only known face-to-face, manualized intervention that specifically targets adolescents with ABI and the family system, (Gan et al., 2010) While there are a few secondary prevention interventions available at this time, there is no published secondary prevention intervention specifically targeting HIV-positive young women.(Hosek et al., 2012) Not just being forced to do traditional physical therapy...(Kashikar-Zuck et al., 2016) In the group for older teens, discussions were often focused on the differences	"[The ChIPS intervention] wasn't easy to find. I was looking for some support for [my son] because he was struggling last year and then rung the Hospital and asked if he could see one of the social workers here. … They said they only had one social worker for the outpatient department and it was all very difficult for them to see him" (Lewis et al., 2016)	Barlow et al., 1999, Gan et al., 2010, Hosek et al., 2012, Kashikar-Zuck et al., 2016, Lewis et al., 2016, Muskat et al., 2016, Wolf-Bordonaro, 2003

Theme: Availability		
	between the pediatric and adult health care system, particularly related to the need for more autonomy, self-advocacy on the part of the teens, and the likely loss of group supports. (Muskat et al., 2016) Therefore, the primary implication is that art therapy be made available to pediatric patients. (Wolf-Bordonaro, 2003)	

		Theme: Availability		
Availability of staff with appropriate training/skills	As may be expected given their realms of expertise, health professionals stressed the medical management aspects more than either parents or children. This emphasis may reflect the domination of health care professionals in the development and delivery of existing interventions. (Barlow et al., 1999) Thus, for example, a mentor’s personality can color the relationship that will develop with a mentee in a number of ways: how much is the mentor prepared to invest in the relationship? To what degree is the mentor able to conduct deep emotional communication? To what degree is the mentor confident in his or her style of coping with diabetes? Mentors who are not prepared to invest a great deal of time beyond that required are not likely to develop a social worker relationship pattern, which is characterized by a high degree of personal willingness to be involved, not only with their mentees, but also with their families and medical practitioners. Mentors who are incapable of conducting deep emotional communication will have difficulty developing a soul mate relationship, which is characterized by deep and revealing conversations...Careful selection of mentors: The second theme in the present study emphasizes that a significant proportion of learning occurs		Barlow et al., 1999, Barnetz et al., 2012, Desai et al., 2014, Fair et al., 2012, Gan et al., 2010, Gillard et al., 2011/13, Stewart et al., 2013a, , Wolf-Bordonaro, 2003	Keeping it going

	Theme: Availability	
	through the encounter of the mentees with adult mentors who are themselves coping with diabetes. As we have seen, this kind of encounter can have positive and meaningful effects, but it can also have negative effects if the mentors are not living in balance with their diabetes. These findings underscore the importance of investigating the degree to which the mentors manage to balance living a meaningful life with responsibly meeting the challenges of diabetes.(Barnetz et al., 2012) Our research adds to the literature by supporting an earlier study which documented that supportive staff–camper interaction is an important process at camp which allows campers to establish meaningful relationships (Gillard et al. 2011). This finding has important implications when training camp volunteers and staff. (Desai et al., 2014) Finally, as noted earlier, the group leaders were not qualified to do formal group therapy. However, the findings are illustrative of the therapeutic benefits of creative writing groups for youth with HIV. Creative writing groups appear to have potential as a clinical tool in the hands of qualified therapists. (Fair et al., 2012) test clinicians stressed the importance of having training in family counselling,	

	Theme: Availability	
	experience with ABI and adolescents and access to peer consultation for clinical support around complex family situations.(Gan et al., 2010) Facilitators were seen as people who were approachable because of their extensive experience providing “raw” HIV/AIDS education to youth...It appeared that some counselors were unprepared to deal with specific issues such as behavioral problems, incidents of sadness or grieving, and disagreements.(Gillard et al., 2011) Camp administrators are urged to strategically plan for opportunities for campers to share concerns and issues about cancer by training counselors to facilitate the discussions. therapists and trainers are more readily available and can be easily trained in the protocol. (Gillard et al., 2013) Peer mentors reported that their training by researchers and the support they received from health professional partners were critical factors in ultimately meeting the support needs of the children(Stewart et al., 2013a) If artists in residence or volunteers were part of a hospital’s arts in medicine program, supervision by a trained art therapist would be crucial in the planning of interventions to meet individual patient’s psychosocial needs, address individual differences, and tackle ethical	

Theme: Availability		
	issues that would arise. (Wolf-Bordonaro, 2003)	

Theme: Availability				
Availability of staff with appropriate training/skills: to consider physical health need	nearly all young people and parents emphasised that having somebody to talk to who was interested in and understood CFS was a key positive feature of therapy sessions.(Dennison et al., 2010) the trainers' ability to modify the exercises to participants' baseline abilities; (Kashikar-Zuck et al., 2016) As well, participants described how other parents should try not to worry because their children will be in capable hands with ‘‘people who can take care of them if anything was to go wrong’’ (White et al., 2016) Furthermore, caregivers identified that their children would be in a safe, inclusive, and non-restricting environment surrounded by health care professionals who would be familiar with their child’s health condition.(White, 2014/16) Thus, considerable expertise, time, and financial resources are required for the development of health-related Internet sites that are accurate and grounded in scientific evidence, use theories of interactive technology, and are acceptable to the targeted population. (Whittemore et al. 2010)	The physiology stuff at the beginning I didn’t find helpful because I don’t think it was fully explained, cause to be honest I don’t think they fully understand it themselves’ (YP5). (Reme et al., 2013)	Dennison et al., 2010, Kashikar-Zuck et al., 2016, Reme et al., 2013, White, 2014/16, Whittemore et al. 2010	Acknowledging physical health needs, Therapeutic Relationships

Theme: Availability			
Protecting others	They cannot be shared with parents because they are overly anxious and concerned, and the mentees are afraid of adding to their worries. (Barnetz et al., 2012) Travers and Lawler (2008) describe a ‘violated’, ‘struggling self’ whose suffering is largely unacknowledged by others and a protective ‘guardianship’ response concerned with self defense, and assuming the burden of proof. The finding that the experience of recognition, validation and being listened to was deemed critical and of importance regardless of treatment effectiveness fits well with this literature. The resistance of the young people to obviously ‘psychological’ aspects of therapy, psychiatric settings, and psychological terms and labels also corresponds to literature concerning discrepancies between lay people and professionals regarding medically unexplained illness. Banks and Prior (2001) describe a ‘political struggle’ between CFS patients and health professionals to construct and frame the problem of CFS and its management. Consideration of the context of CFS and patients’ deligitimising experiences and invalidating encounters prior to entering psychological treatment are clearly relevant to understanding responses to psychological interventions.(Dennison et al., 2010)		Barnetz et al., 2012, Dennison et al., 2010, Docherty et al., 2013, Weekes et al., 1993

Theme: Availability

The second core theme centered on parents' discussions of AYA participation decisions. Some parents described an initial hesitancy from AYA when asked to participate in the study. This was related to disinterest in study activities, efforts to protect parents from painful aspects of the AYA's experience,...Previous research has described the difficulties that very ill children and adolescents experience when trying to communicate painful experiences with their parents [3]. During cancer treatment, AYA distress-coupled with efforts to avoid distressing parents – often stifle AYA-parent communication about cancer-related concerns (Docherty et al., 2013)

Those adolescents who decided not to hold someone's hand gave reasons such as fear of hurting the person's hand, unavailability of the preferred person (usually mother), or that no one offered then a hand to hold and they were embarrassed to ask (Weekes et al., 1993)

Theme: Accessibility

Theme: Accessibility				
Idea for further interpretation/ Third Order Construct	Second Order Construct	Quote	Papers contributing	Acknowledgement of overlap
Relationships with professionals facilitating access to intervention.	However, attendance at the event also required support and affirmation by family and/or health professionals and practical help, e.g., dropping off the young person at the venue: (Campbell et al., 2010) Familiarity with their cardiologists may provide the initial confidence necessary for children and their parents to make the decision to attend camp. (Desai et al., 2014) Parents and guardians reported few concerns. Most had long-standing relationships with the social worker who first introduced the idea of a creative writing group....Group leaders cited a strong connection with social workers and other community resources as fundamental to the success of a creative writing group for adolescents living with HIV(Fair et al., 2012) First, children and youth services professionals and others should consider recommending a medically-supported summer camp to eligible adolescent patients. Adolescents living with serious illness do not typically have many opportunities to engage in a developmentally supportive youth context, and the developmental supports found in medical summer camp can help	“You’ve got the teachers, you’ve got the wards, you’ve got the social workers. It should be just part and parcel of coming around on discharge, you know that you are aware that there is support for young people, maybe not now, but when it may be appropriate.” (Lewis et al.,2016, p2547)	Campbell et al., 2010, Desai et al., 2014, Fair et al., 2012, Gillard et al., 2016; Nicholas et al., 2007, Lewis et al., 2016, Moola et al., 2015, Wolf-Bordonaro, 2003	Could acknowledge choice for CYP here?

	Theme: Accessibility	
	youth gain a sense of normalcy in personal and social experiences that is otherwise absent.(Gillard et al., 2016) New members entered ChIPS primarily by parent referral or by co-ordinator invitation. A few were also referred by members of their multi-disciplinary hospital care team (MDT)....Young people had various memories of how they came to ChIPS. One remembered being referred by her physician (ChIPS Reference Group).(Lewis et al., 2016) More recently, as the ChIPS Reference Group has become more established, co-ordinators have identified young people who they think would benefit from participating in the Introductory Program. For example, co-ordinator 4 told us: (Lewis et al., 2016) In particular, they might consider purposefully engaging CHD patients with greater functional disability who come from socio-economically deprived and ethnic and racial minority groups. The inclusion of these ‘silent voices’ in both camp and camp related research might work towards parody in camp programming. (Moola et al., 2015) All children became engaged in SBW following an invitation from a pediatric health care professional....Clearly, social workers, child life specialists and other health care professionals play an important role in informing children and	

Theme: Accessibility		
	adolescents about the network....Social workers and other health care professionals play a substantial role in introducing this notion, particularly as teens are initially strangers. (Nicholas et al., 2007) Additionally, upon the initiation of a hospital art therapy program, a referral system involving families, nurses, and other hospital staff, could be implemented;...(Wolf-Bordonaro, 2003)	

Theme: Accessibility			
Methods of invitation/access	New members entered ChIPS primarily by parent referral or by co-ordinator invitation. A few were also referred by members of their multi-disciplinary hospital care team (MDT). (Lewis et al., 2016) In the future, it may be important to consider the kind of participants who partake in camp-based research. While there was much diversity within our sample, most participants were middle class and functioned well with their cardiac illness. The history of camp itself is heavily influenced by Euro-Western notions of middle-class muscular Christianity, and may be quite a foreign concept to sick children from diverse ethnic and cultural backgrounds. It may also be the case that sick children who experience the greatest functional disability and socio-economic marginalisation – and arguably need camp the most to reap the psychosocial benefits – do not attend (Moola et al., 2015 et al. 2013). Camp programmers, clinicians and researchers should perhaps examine whether the camp demographic is representative of the patient demographic. In particular, they might consider purposefully engaging CHD patients with greater functional disability who come from socio-economically deprived and ethnic and racial minority	“I got a letter and there were instructions. I think I opened it, I’m not sure. I had heard about it before from Mum. I’m not sure how Mum heard about them. I decided to go. I got the bus and then got lost so I went home and Mum dropped me off. I never knew (name of venue) was in the centre (of town).” (Campbell et al., 2010) “No, she just, like, told, I don’t know who, but someone about ChIPS and then they contacted us. Girl 4: I met (ChIPS Co-ordinator) at a Turner’s conference in late December and she recommended me for ChIPS. And I got a text message saying would I like to come along.”(Lewis et al., 2016)	Campbell et al., 2010, Griffiths, Lewis et al., 2016, Moola et al., 2015, Nicholas et al., 2007, O’Callaghan et al., 2013, Wolf-Bordonaro, 2003

	Theme: Accessibility	
	groups. The inclusion of these ‘silent voices’ in both camp and camp related research might work towards parody in camp programming. (Moola et al., 2015) Social workers and other health care professionals play a substantial role in introducing this notion, particularly as teens are initially strangers. (Nicholas et al., 2007) Some agree to music therapy only after observing other children’s sessions. They maybe “vicariously” engaged even though apparently disinterested. For example, a 4-year-old boy who, the previous week, had appeared distressed during medical consultations and disinterested in overheard music therapy, wanted to returned the following week to “the instrument hospital,” ready to meet the therapist. Another 9-year-old boy with a life-limiting brain stem tumor rejected but observed music therapy for 3 weeks before composing and recording a song about his love for his “cheeky” baby sister. After “singing her praises” the song ended with, “Now go to sleep!” (O'Callaghan13) Additionally, upon the initiation of a hospital art therapy program, a referral system involving families, nurses, and other hospital staff, could be implemented;... Furthermore, if the researcher chose to	

Theme: Accessibility		
	work with patients with chronic medical conditions, the research might be implemented with outpatient groups, rather than in the hospital setting. (Wolf-Bordonaro)	

Theme: Accessibility			
Health of child as (potential) barrier	Another child talked about how she could not attend a ‘‘normal’’ camp because of her medical needs and felt ‘‘safe’’ and protected participating in this camp. (Bultas et al., 2015) Although parents experienced sheer joy in having the video as a final product, they also expressed varying levels of regret that they had not spent more time finding pictures and that the AYAs had not felt well enough to put even more time into the project. (Burns et al., 2010) Challenges generally occurred when visitation was limited because of infection control procedures (Burns et al., 2010) It was also important that parents were present to absorb the advice since young people often reported extreme The location of the therapy sessions (South London) was an issue. The travelling and the sessions themselves left the young people feeling drained and struggling to participate fully.(Dennison et al., 2010) Parents suggested ideas for adjusting the intervention process to avoid periods of high physical distress.(Docherty et al., 2013) Another way that feelings of reprieve and recreation were planned for at camp was through the structural and social accessibility of all activities, based on the facilities and programming philosophy. Discover Camp was intentional about	Julie talked about how it was difficult for her and her daughter to attend the sessions because of Leticia’s treatment. “R: Was Living Well what you expected it to be? P: We were only there twice, so yeah, I liked it. I think i f s just more stressful when new things are changing and stuff like that. So, I would say because we have to do something every day, it’s kinda like, if you were not going to the doctor all the time and new things developing, it would be Reproduced with permission of the copyright owner better to wait until after that phase to actually get the full benefit of the program . Participant (Brodeur, 2005) “It was so hard to watch. She was so exhausted and not going to bed it was so painful” (P 1 2 CBT) (Dennison et al., 2010)	Brodeur, 2005, Bultas et al., 2015, Burns et al., 2010 Dennison et al., 2010, Docherty et al., 2013, Gillard, 2011; Gillard, 2013, Kashikar-Zuck et al., 2016, Kirk et al., 2016, Lewis et al., 2016, Marsac et al., 2012, Nicholas et al., 2007, O’Callaghan et al., 2013, White et al., 2014/2016, ,

	Theme: Accessibility
	making camp “barrier free,” and both campers and staff perceived that the camp activities were accommodating to all participants. For example, the ramp to the canoes was designed so that campers could typically enter canoes without assistance, and canoes could accommodate two or three helpers if necessary. Bean-bag chairs were placed into canoes so that campers with mobility or strength impairments could go out onto the lake in canoes.(Gillard et al., 2011) he philosophy of camp was that it was not only accessible; but also “barrier-free.” Medical staff members were well aware of the health needs of individual campers, and ensured that appropriate staff and equipment were available to facilitate their participation in camp. (Gillard et al., 2013) If I'm already hurting probably won't do them as much. Flare-ups, because sometimes it is just easier to get into this mindset that...I am just going take it easy today. When sometimes getting up and moving makes it better, but while it is going on it is hard to remember that. I'll be too tired to practice exercises).(Kashikar-Zuck et al., 2016) However, incorporating peer support for young people with CF has been previously constrained by physical segregation policies. (Kirk et al., 2016)

	Theme: Accessibility	
	The third barrier was medical. Young people missed ChIPS meetings when they became acutely unwell. ChIPS co-ordinators also spoke of young people missing ChIPS meetings because … some families won’t bring them back to the hospital when they’re not sick because they don’t want to catch infections. (Co-ordinator 1) (Lewis et al., 2016) families identified potential barriers to using the Cellie Kit: soft toy limitations during parts of treatment (e.g., bone marrow transplant), (Marsac et al., 2012) Children’s decision to participate in SBW was influenced by a variety of factors. Identified influences included: feeling well enough to participate, Nicholas et al., 2007) e mother observed that the computer used by her child was located, “down in (the children’s) lounge, and we didn’t always get a chance to get down there . . . when he was really sick.” (Nicholas et al., 2007) also, children may not wish to participate. They may feel too unwell, have reduced sound tolerance, (O’Callaghan et al., 2013) I think for the parents—a peace of mind—that you know if something happens to your child they’re in good hands. If I sent her off to a week long camp somewhere else and she goes in and she can’t breathe and needs to sit,	

Theme: Accessibility		
	they’re going to panic… they’re going to call the ambulance and it’s going to be a big traumatic event for her. If she’s at Camp Oki and she has an issue they’ll be like, ‘ok let’s sit for a minute, see how you feel’—they know the symptoms. And I don’t have to give them sheets and sheets of information on, ‘this is what you have to do if this happens’. The fact that she can go to Camp Oki and I don’t have to worry about the heart issue is amazing! (Julie) (White et al., 2016) Furthermore, caregivers identified that their children would be in a safe, inclusive, and non-restricting environment surrounded by health care professionals who would be familiar with their child’s health condition. (White, 2014)	

Theme: Accessibility			
Adaptation of intervention to individual needs to make more accessible (psycho/social/behavioural/emotional only)	Some young people and parents also mentioned disliking feeling pigeonholed and subjected to generalisations. (Dennison et al., 2010) Parents appreciated the flexibility of the intervention to accommodate changes in AYA distress, support AYA’s need for privacy and independence, and support or renew important relationships for their AYA. (Docherty et al., 2013) For program structure, the participants reported preferring a combination of individual and group meetings.(Hosek et al., 2012) programme exercises were modified to include diabetes-specific problems and stressors; (Serlachius et al., 2012) The participant-respondents emphasized the importance of integrating formal and informal discussion and activities in camps to maximize mutual support. (Tiemans et al., 2007) All caregivers perceived camp as a pleasurable setting where their children’s anxieties would be addressed, which would further lead to improvements in their self-confidence. (White, 2014) became more comfortable and confident in this role as time progressed. It was apparent in this program that the core responsibility levels of the PSRM were made relevant to participants. Each participant brought unique strengths as well as struggles to the program and	Another health care staff member discussed that “I think it's a protected environment for them and lets them close the world to all the badness that's going on around them. Especially if kids are near the end.” (Gillard et al., 2013)	Dennison et al., 2010, Docherty et al., 2013, Gillard et al., 2013, Hosek et al., 2012, Serlachius et al., 2012, Tiemans et al., 2007, White et al., 2014, Wright et al., 2004

Theme: Accessibility	
	required an individualized approach. (Wright et al., 2004)

Theme: Accessibility			
Adaptation according to the age (and needs associated with age) and educational level	The need to target children of different ages was apparent. For example, adolescence is a sensitive time that may demand a specific approach addressing the salient issues….New technologies, such as multi-media computing, may offer a means of meeting specific needs through individualized paths of learning that take account of developmental level and different perspectives. (Barlow et al., 1999) These additional studies should include younger children and children in varying stages of cancer treatment to determine if the BOC Program description changes based on age, and stage of treatment. (Baruch, 2012) Age-appropriate and appeals to adolescents or young adults (AYAs) (Burns et al., 2010) All participants were at the age at which sex and sexuality were important issues and they were aware of the difficulties that disclosure of their status might pose to potential partners (Campbell et al., 2010) Potentially the difficulty engaging with the cognitive aspects described by some patients could be due to age and maturity levels making it difficult to analyse personal thoughts at a meta-level. (Dennison et al., 2010) Prior to camp, adult staff adjusted programming plans to accommodate the	"CD, it was more easier to do than reading it'' (Bignall et al., 2015) Art projects. Some participants would have made some changes to the art projects. "I thought that some of the activities, even though they were family oriented activities, I felt that they were a little, over the age range of little kids."(Brodeur, 2005)	Barlow et al., 1999, Baruch, 2012, Brodeur, 2005, Burns et al., 2010, Campbell et al., 2010, Dennison et al., 2010, Gillard et al., 2011, Hosek et al., 2012, Marsac et al., 2012, Nicholas et al., 2007, Serlachius et al., 2012, Whittemore et al. 2010, Wolf-Bordonaro, 2003

Theme: Accessibility		
	needs of campers. Staff planned activities to be age appropriate (i.e., older campers engaged in more complex activities), to account for fatigue issues associated with HIV/AIDS and the heat of late July in the southern United States, and to maintain high counselor–camper ratios (Gillard et al., 2011) The camp promoted a social context that was characterized by high degrees of caring relationships, which were especially valued given the need for positive developmental experiences for youth living with cancer. (Gillard et al., 2013) In our evaluation of the ability of children to understand the coping cards, children with cognitive skills below those for an average of 7 years old would likely need more support in implementing the tips on the cards. For older children (over age 11) who perceive the Cellie toy as childlike, the cards and book could be used without the toy.(Marsac et al., 2012) Health care professionals introduced a child to the network after considering the child’s potential interest and suitability for computer use, language literacy, and eye/hand coordination....Given adolescents’ frequent propensity for peer engagement, finding supportive interaction among peers appears potentially relevant for this adolescent population (Nicholas et al., 2007)	

	Theme: Accessibility	
	It’s probably a good idea to get to know what people the same age (Serlachius et al., 2012) Teenagers who disliked the site felt that it was more appropriate for adults and needed to be more interactive. (Whittemore et al. 2010) Given the developmental impediments depicted in Figure 1’s drawings (and to a lesser extent by the simplified stick figures produced by Subject 2), the drawing directive itself may have been exigent. The required abstract thinking regarding time may be particularly problematic for the 6 year-old Subject 1. This will be an important consideration for practice for this, and comparable populations....For example, it became apparent that the youngest of the three subjects in this study may not have been able to form complete cognitions for the abstractions of time essential to the final intervention (the Before-During-and-After Drawing Series). Alternative instructions, interventions, or vocabulary may be useful in working with individual patients. (Wolf-Bordonaro, 2003)	

Theme: Accessibility			
Adaption of intervention to meet physical need/Disability/specific LTC issue	The need to target children of different ages was apparent. For example, adolescence is a sensitive time that may demand a specific approach addressing the salient issues….New technologies, such as multi-media computing, may offer a means of meeting specific needs through individualized paths of learning that take account of developmental level and different perspectives. (Barlow et al., 1999) Age-appropriate and appeals to adolescents or young adults (AYAs) (Burns et al., 2010) All participants were at the age at which sex and sexuality were important issues and they were aware of the difficulties that disclosure of their status might pose to potential partners (Campbell et al., 2010) Potentially the difficulty engaging with the cognitive aspects described by some patients could be due to age and maturity levels making it difficult to analyse personal thoughts at a meta-level...nearly all young people and parents emphasised that having somebody to talk to who was interested in and understood CFS was a key positive feature of therapy sessions. (Dennison et al., 2010) Another 11-year-old camper who recognized counsellors' role in setting boundaries and monitoring camper activity levels expressed his sense of	‘‘people who can take care of them if anything was to go wrong” (White et al., 2016)	Barlow et al., 1999, Burns et al., 2010, Campbell et al., 2010, Dennison et al., 2010, Desai et al., 2014, Gan et al., 2010, Gillard et al., 2011/13; Kashikar-Zuck et al., 2016, Lewis et al., 2016, O'Callaghan et al., 2013, Serlachius et al., 2012, Stewart et al., 2011b, Stewart et al., 2013a; White et al., 2014/16, Wolf-Bordonaro, 2003

	Theme: Accessibility	
	security, ‘the counsellors make sure you don’t do too much stuff we are not supposed to do.’ (Desai et al., 2014) Prior to camp, adult staff adjusted programming plans to accommodate the needs of campers. Staff planned activities to be age appropriate (i.e., older campers engaged in more complex activities), to account for fatigue issues associated with HIV/AIDS and the heat of late July in the southern United States, and to maintain high counselor–camper ratios (Gillard et al., 2011) The camp promoted a social context that was characterized by high degrees of caring relationships, which were especially valued given the need for positive developmental experiences for youth living with cancer. (Gillard et al., 2013) the findings are unique in that the target population directly informed future intervention content and requested an intervention that is multidimensional, comprehensive, and tailored to their gender and age. (Hosek et al., 2012) Not just being forced to do traditional physical therapy... with this being catered towards people with fibromyalgia ...the trainers' ability to modify the exercises to participants' baseline abilities; (Kashikiar-Zuck)	

Theme: Accessibility		
	More recently, as the ChIPS Reference Group has become more established, co-coordinators have identified young people who they think would benefit from participating in the Introductory Program. For example, co-ordinator 4 told us: “Co-ordinator 4: I scour [the hospital database] and see who’s in [hospital] and who might be a good candidate, and soResearcher: Ok, so who might be a good candidate, compared to someone who’s not a good candidate? Co-ordinator 4: Ah, ok, so we take anyone from 12 and up …we don’t take eating disorder patients because they have a different set of needs to chronically ill kids and you can see that divide just on the ward. So, our Crohn’s patients and our transplant patients and everything. “(Lewis et al., 2016) Another theme across all groups was the desire for more diabetes-specific information and skills. Through instrumental play and improvisations, those unable to verbally engage (e.g., preverbal, unable to speak English) can interact with someone other than their family. (O'Callaghan13) This feedback is consistent with intervention studies in T1DM that have demonstrated the advantages of providing diabetes specific interventions, in order to meet the unique needs of the	

Theme: Accessibility		
	patient group (Serlachius et al., 2012) For adolescents minimally affected by disability and for those with severe disabilities that impeded full participation, benefits are more difficult to assess. (Stewart et al., 2011b) Most parents believed that by being able to talk to other children and being part of a group with others with the same health condition and experiences made the children’s support group effective. (Stewart et al., 2013a) Furthermore, caregivers identified that their children would be in a safe, inclusive, and non-restricting environment surrounded by health care professionals who would be familiar with their child’s health condition. (White, 2014)	

Theme: Accessibility				
Flexible to individual needs	Some parents felt the agenda during the sessions was too narrow and rigid and therefore unresponsive to families' idiosyncratic issues. (Dennison et al., 2010) They attributed their confidence to the type of activities tailored to meet their needs, responsive supervision, and the unconditional acceptance they felt at camp.(Desai et al., 2014) For now, it is important that a variety of modalities be available for families to choose from, rather than expecting that one size fits all. (Gan et al., 2010) The psychotherapist noted that many participants brought up sleep as a problem area, and there were no specific instructions on sleep hygiene in the CBT protocol. (Kashikar-Zuck et al., 2016) Parents acknowledged that the children gained information, but also noted that their children's confidence and empowerment was enhanced by interactions with peer mentors who helped make information relevant to their needs (Stewart et al., 2013a) The content for the group sessions was initially designed based on assessment from child and parent perspectives, and then individual weekly sessions were subsequently adapted to the unique and changing needs of each group.(Wolf-Bordonaro, 2003) While most children seemed to derive		Dennison et al., 2010, Desai et al., 2014, Gan et al., 2010, Kashikar-Zuck et al., 2016, Stewart et al., 2013a, Wolf-Bordonaro, 2003, Wright et al., 2004	Relevance and…Empowerment

Theme: Accessibility		
	some social benefits from the program, this was not true for all. James was already very mature and not lacking in social development when he entered the program. Neither his mother nor his therapist could attribute any changes in this regard to the program. (Wright et al., 2004)	

Theme: Accessibility			
Flexibility to consider personality/likes/dislikes	The pairing stage: This stage should be approached solemnly and painstakingly. After getting to know all the mentors and mentees, it is advisable to consult with professionals on pairing mentors and mentees, and to take into account matching mentor/mentee gender, the mentors’ skills to the needs and wishes of the mentees, and matching fields of interest, temperament, and style. (Barnetz et al., 2012) These additional activities may be important for AYAs who do not especially enjoy music. (Burns et al., 2010) These individuals held strong preferences for physiological explanations of CFS and deemed physiological approaches more useful and relevant. ‘But the thing is it was actually useless. It wasn’t even like something that might have helped. It was completely useless’ (YP 6 2 PE). (Dennison et al., 2010) Another stated, “I was thinking. . .we could learn the basics of the language of other cultures and the different clothing designs and stuff since a whole lot of people in there like fashion and stuff like that.” (Fair et al., 2012) The second and third barriers were expected; not all children are interested in or bond with the same toys, and (Marsac et al., 2012) Health care professionals introduced a		Barnetz et al., 2012, Burns et al., 2010, Dennison et al., 2010, Fair et al., 2012, Marsac et al., 2012, Nicholas et al., 2007, Shrimpton et al., 2013

Theme: Accessibility		
	child to the network after considering the child’s potential interest and suitability for computer use, language literacy, and eye/hand coordination. (Nicholas et al., 2007) produced a sense of a more personalised treatment process whereby the child, rather than their illness, was recognised, made to feel special and cared for. (Shrimpton et al., 2013)	

		Theme: Accessibility	
Delivery Mechanism	As was noted in the evaluation of the TOPS family intervention [28], some adolescents and parents may actually prefer face-to-face interventions, despite the appeal, convenience and accessibility of technology. (Gan et al., 2010) For program structure, the participants reported preferring a combination of individual and group meetings.(Hosek et al., 2012) However, many participants indicated that they did like the phone calls because of the personalized attention they received from the caller. Comparison of an automated text message delivery system versus personalized phone calls may aid in determining which delivery system is most effective and convenient for the participants. (Jaser et al., 2014) A few parents thought the online meeting sessions were good, but wanted an additional face-to-face meeting during the intervention. Some said that to help them bond, children could meet face-to-face before the online support group began, but others thought that an in-person meeting would be preferable after the children became acquainted virtually.(Stewart et al., 2013a) This camper recommended blending professional leadership and peer support to maximize psychosocial goals. (Tiemans et al., 2007) With the advent of online social		Gan et al., 2010, Hosek et al., 2012, Jaser et al., 2014, Stewart et al., 2013a, Tiemans et al., 2007, Whittemore et al. 2010

Theme: Accessibility		
	networks, instant messaging, and text messaging, e-mail may not be the preferred method of communication for adolescents.(Whittemore et al. 2010)	

Theme: Accessibility			
Flexibility Gender	The pairing stage: This stage should be approached solemnly and painstakingly. After getting to know all the mentors and mentees, it is advisable to consult with professionals on pairing mentors and mentees, and to take into account matching mentor/mentee gender, the mentors' skills to the needs and wishes of the mentees, and matching fields of interest, temperament, and style. (Barnetz et al., 2012) the findings are unique in that the target population directly informed future intervention content and requested an intervention that is multidimensional, comprehensive, and tailored to their gender and age. (Hosek et al., 2012) In the future, it may also be important to consider gendered differences in the camp experience in the future. (Moola et al., 2015) Gender should be considered in future research...The intervention may appeal more to females or there may be an interaction with age as males were younger (M ¼ 14.2) than females (M ¼ 15.2). Diagnosis should be considered. Adolescents with cerebral palsy identified more negative interactions in social networks; however, negative contacts decreased after intervention (Table 3). They sought support more as a coping strategy and reported more loneliness.(Stewart et al., 2011b)		Barnetz et al., 2012, Hosek et al., 2012, Moola et al., 2015, Stewart et al., 2011b,

Theme: Accessibility			
Adaption for stage of illness/Life stage	All participants were at the age at which sex and sexuality were important issues and they were aware of the difficulties that disclosure of their status might pose to potential partners (Campbell et al., 2010) Children and parents wanted relevant information from the point of diagnosis and onwards throughout the course of the disease...Standardized approaches attempting to meet universal needs may be confusing and distressing for individual families who may be cited at differing points on the disease spectrum. (Barlow et al., 1999) Timing of BIFI-A delivery Even though many families commented that this intervention would be very useful in the early stages following the brain injury (Gan et al., 2010) The work is not formulaic and may occur from the child's diagnosis, through treatment, and palliative care if sadly needed. (O'Callaghan et al., 2013) The Lightning Process was described as involving hard work, although those who had suffered from CFS the longest tended to view it as harder than those who had not suffered as long. (Reme et al., 2013) as newly diagnosed adolescents are still adjusting to having a chronic illness and those with comorbidities face many additional stressors and challenges. (Serlachius et al., 2012)	In two of the groups participants indicated they wanted to review the information they were given when they were newly diagnosed. They also acknowledged they were confused about certain aspects of their treatment regimen: "Like maybe a second education meeting, where you can ask questions. Because I remember when I got educated for the first time, I was totally lost" (Serlachius et al., 2012)	Barlow et al., 1999, Campbell et al., 2010, Gan et al., 2010, O'Callaghan et al., 2013 Reme et al., 2013, Serlachius et al., 2012, Wolf-Bordonaro, 2003

Theme: Accessibility	
	The Before-During-and-After Drawing Series was the least effective intervention of the protocol. The intervention would have better served pediatric patients hospitalized with acute, rather than chronic, conditions. (Wolf-Bordonaro, 2003)

Theme: Accessibility			
Time of sessions/demands of practise or attendance	and/or family or friends lived far away from the hospital. (Burns et al., 2010) However, there were competing priorities during school holidays and attendance at the LFP was not always a priority: My Dad told me about the day. I have been to a few now but I had to miss one because I was busy doing a dance show but I would have come otherwise. (John, 15 (Campbell et al., 2010) Dropped Out (n = 6) o Psychiatric referral (n = 1) O Employment interference (n = 1) W o Time/transportation (n = 4)...1 started employment that interfered with program completion, and 4 others had difficulty making regular appointments and transportation arrangements. ...Also, we moved the sessions to after school hours which were preferable to families. (Kashikar-Zuck et al., 2016) The focus groups were scheduled outside normal hospital clinical hours and outside normal ChIPS talking group hours. Their schedule might, therefore, have conflicted with other regular commitments of ChIPS members, their parents, or siblings. (Lewis et al., 2016) Most parents liked online delivery as it accommodated family schedules and children could participate independently. (Stewart et al., 2013a)	"The only thing I would change, and that's from having older kids and mine were older than most of the others, would have been a weekend or a Friday night because of the homework and getting downtown and coming back. That was pretty much a 2-1/2 hour, 3-hour venture by the time we left and came back. Now that I'm working, it would be almost impossible." (Brodeur, 2005)	Brodeur, 2005, Burns et al., 2010, Campbell et al., 2010, Kashikar-Zuck et al., 2016, Lewis et al., 2016, Stewart et al., 2013a,

Theme: Accessibility			
Place of sessions/Travel/financial burden	Results also indicated that this intervention is feasible in a school based setting and acceptable to this population of youth. (Bignall et al., 2015) and/or family or friends lived far away from the hospital. (Burns et al., 2010) The location of the therapy sessions (South London) was an issue. The travelling and the sessions themselves left the young people feeling drained and struggling to participate fully.(Dennison et al., 2010) Two guardians mentioned that the long trip to the group site was inconvenient, though it did not deter participation due to their longstanding relationship with the social worker. (Fair et al., 2012) Dropped Out (n = 6) o Psychiatric referral (n = 1) O Employment interference (n = 1) W o Time/transportation (n = 4) (Kashikar-Zuck et al., 2016) The first barrier was personal. Parents found the weekly trips to the hospital to be draining of their time and emotional resources. (Lewis et al., 2016) Medical teams could work with children using the Cellie Kit during appointments to reduce the burden on the family. (Marsac et al., 2012) address practical barriers to attendance (i.e., transportation),...The physical location of support services, particularly for populations facing economic	However, attendance at the event also required support and affirmation by family and/or health professionals and practical help, e.g., dropping off the young person at the venue: “I got a letter and there were instructions. I think I opened it, I’m not sure. I had heard about it before from Mum. I’m not sure how Mum heard about them. I decided to go. I got the bus and then got lost so I went home and Mum dropped me off. I never knew (name of venue) was in the centre (of town).” (Campbell et al., 2010) “I think it’s good that it’s inside the hospital so we don’t have to go to too much places.” (Muskat et al., 2016)	Bignall et al., 2015, Burns et al., 2010, Campbell et al., 2010, Dennison et al., 2010, Fair et al., 2012, Kashikar-Zuck et al., 2016, Kirk et al., 2016, Lewis et al., 2016, Marsac et al., 2012, Muskat et al., 2016, Reme et al., 2013, Stewart et al., 2013a

Theme: Accessibility		
	challenges, is important to consider.(Muskat et al., 2016) The cost was also mentioned as a negative aspect.(Reme et al., 2013)	

		Theme: Accessibility		
Burden of sessions (Pacing, Length, Emotional safety, Understandability)	Although health professionals were aware of the need to inform children and parents about JCA and its treatment, they advocated a cautious approach. They were concerned that too much information would cause anxiety. (Barlow et al., 1999) The lunch also offered a break from what could be an emotional experience, Whilst participants found it helpful to be with other HIV' young people, they sometimes found an explicit focus on HIV difficult. (Campbell et al., 2010) The behavioural aspects of the therapy emerged as being particularly valued and accepted by the young people who found these easy to 'latch on to'. (Dennison et al., 2010) It was recommended that the intervention include only one topic per session but that there be the option of combining topics if desired and appropriate...Some of the adolescents had difficulty remaining engaged in the sessions and it was suggested that more interactive activities be added to each session. Paper and pencil tasks also needed to be reduced. In general,...There was additional feedback regarding specific handouts and activities to improve readability and flow of sessions....The ideal length of the session was felt to be 45–60 minutes. (Gan et al., 2010)	"An hour is really not long enough to do some of the things (art projects) that we do without somebody finishing it up for us" (Brodeur, 2005) Shared concerns among group leaders included the length of the group, finding a balance between recreation and academics, and the potential emergence of discussion about sensitive topics. A group leader explained: "I thought, they're in here from like 10-2, they're going to rebel, they're not going to want to do it. . .it's like school! So that was a risk." (Fair et al., 2012) but several comments were raised regarding the intensity of the treatment, such as the following: "It was really, really taxing the first day because it started at 10 and didn't finish until about seven in the evening, and there were also about seven other people there which is like…considering I had been like housebound for years I hadn't really got…like, saw anyone, it was like quite a massive thing. And by the end of the first day I was absolutely shattered" (YP2). (Reme et al., 2013) "was very vocal during the meetings. It was well done. It	Barlow et al., 1999, Brodeur, 2005, Campbell et al., 2010, Dennison et al., 2010, Fair et al., 2012, Gan et al., 2010, Gillard et al., 2013, Jaser et al., 2014, Kashikar-Zuck et al., 2016, Marsac et al., 2012, Muskat et al., 2016, Reme et al., 2013, Serlachius et al., 2012, Stewart et al., 2013a, Whittemore et al. 2010, Wolf-Bordonaro, 2003	Setting

	Theme: Accessibility		
	Teens consistently identified some exercises as being the most difficult, particularly those including squats, hamstring curls, lying prone while extending arms and legs (Superman), and hip hinge on 1 leg. (Kashikar-Zuck et al., 2016) The cognitive interview in study 1 revealed that most children could understand the material on the coping cards; 12 out of 15 children (80 %), completing the cognitive interview, were judged to have sufficient understanding of all five cards presented to them. Three children had difficulty understanding the cards due to cognitive limitations. Specifically, one 6 year-old and two children with treatment-related cognitive impairments were unable to explain how to use the tips on the coping cards without assistance. Given that only the youngest children and children with cognitive limitations had difficulty understanding the Cellie Kit materials, no revisions were deemed necessary based on comprehension of the materials. In study 1 (Cellie Kit comments), all parents reported that the book was easy to understand and that they would be able to enact the coping tips without guidance, and most (n013; 87 %) reported that their child could understand the coping cards. In study 2 (pilot intervention feedback),	wasn’t too long; it just worked out well.” (Mother of two daughters with allergies) (Stewart et al., 2013a)	

	Theme: Accessibility	
	most families completing the follow-up assessment indicated that the coping cards were easy to use, and most children reported that they knew “how to use the Cellie Kit” (see Table 2). Reasons children provided for not knowing how to use it included completing treatment and not needing it. (Marsac et al., 2012) The convenience of having medical and psychosocial care in one location lessens the burden of care and, if delivered effectively, increases the likelihood of participation in both. (Muskat et al., 2016) However, several aspects of the Lightning Process were considered unhelpful. The length of the sessions was thought to be too long and intense, especially since many of the participants struggled with focus and concentration. (Reme et al., 2013) was very vocal during the meetings. It was well done. It wasn’t too long; it just worked out well. (Mother of two daughters with allergies) (Stewart) They expressed strong feelings that they did not want it to resemble school-based activities that involve testing, repetition, or competition.. An important suggestion for improvement included simplifying some of the problem-solving exercises.	

Theme: Accessibility		
	(Whittemore et al. 2010) For example, it became apparent that the youngest of the three subjects in this study may not have been able to form complete cognitions for the abstractions of time essential to the final intervention (the Before-During-and-After Drawing Series). Alternative instructions, interventions, or vocabulary may be useful in working with individual patients. (Wolf-Bordonaro, 2003)	

Theme: Accessibility				
Graphics/format of info	There was additional feedback regarding specific handouts and activities to improve readability and flow of sessions. (Gan et al., 2010) Providing diabetes education in a simple, albeit engaging format (with visually appealing graphics and fonts) targeted for adolescents appears to be acceptable to adolescents as they transition to more autonomous diabetes self-management. (Jaser et al., 2014) The information given in the first session was also described as difficult to understand, challenging, and some of it also in conflict with what other therapists had told them. ‘One thing I found was that…being under a specialist and doing the Lightning Process…sometimes their advices conflicted’ (YP3). (Reme et al., 2013) The Managing Diabetes site was revised to have greater visual appeal by decreasing text and increasing pictures of diverse teenagers. (Whittemore et al. 2010) For example, it became apparent that the youngest of the three subjects in this study may not have been able to form complete cognitions for the abstractions of time essential to the final intervention (the Before-During-and-After Drawing Series). Alternative instructions, interventions, or vocabulary may be useful in working with individual patients.		Gan et al., 2010, Jaser et al., 2014, Marsac et al., 2012, Reme et al., 2013, Whittemore et al. 2010, Wolf-Bordonaro, 2003	Engagement

Theme: Accessibility
(Wolf-Bordonaro, 2003)

Theme: Accessibility			
Not Long enough/too long	In addition, the interventionists noted that the length of sessions (60 min) was too short-there was not enough time to review homework in addition to learning and practicing new material (CBT and exercises). (Kashikar-Zuck)	“An hour is really not long enough to do some of the things (art projects) that we do without somebody finishing it up for us, which is fine, no problem with that, but it seems to me that I’ve said all along that I’d like to see it expanded a little bit longer, but I know you have the confines of the museum, with the time that we have to be in and out of there and so forth, so I’m not sure how you would be able to do that, but what about if you took a project and you took it to the next week. Now, sometimes families are not going to be there, but what’s wrong with them picking it up when they come back the next time, or if they don’t want to, they want to start on the next project that’s being presented, then do it. I mean, two week projects you could do a little bit more detailed stuff and know that you are going to have the time to finish it up. I mean there are all kinds of things. And what if you had the idea of doing something large that we could then take and donate to the hospital, donate to Children’s hospital, just give it back to the community in some capacity? Something that you could make for assisted living, or a	Brodeur, 2005, Kashikar-Zuck et al., 2016

Theme: Accessibility
nursing home environment. So if you allow yourself the luxury of a big long term project like that, it doesn’t matter if every family is there every week or not because you still have people working on it every week.” (Brodeur, 2005)

Theme: Accessibility			
Technology/Online facilitating access/barriers	New technologies, such as multi-media computing, may offer a means of meeting specific needs through individualized paths of learning that take account of developmental level and different perspectives. (Barlow et al., 1999) some adolescents and parents may actually prefer face-to-face interventions, despite the appeal, convenience and accessibility of technology.(Gan et al., 2010) Technology-Based Challenges Several participants identified barriers to network utilization as a result of technology-based problems and/or personal challenges using the computer. For instance, a child had difficulty remembering his online password: “You would need a password to log in and I forgot mine....”A parent described system difficulties with the computer: “Sometimes (the ill child) gets a bit frustrated...because (the computer) freezes.” A few participants described instances when accessibility to others for videoconferencing had been prohibitive. For instance, participants described being unable to find a videoconference partner with whom to “meet” and communicate. When a partner was found, occasional software problems were noted in connecting with that individual (e.g., difficulty deciphering the computer-mediated voice, not receiving the video		Barlow et al., 1999, Gan et al., 2010, Kirk et al., 2016, Jaser et al., 2014, Nicholas et al., 2007, Stewart et al., 2013a,

Theme: Accessibility		
	picture, delayed response, connection loss). A parent described challenges in connecting: “The other thing is timing because by the time you get down there (to the playroom), and on (the computer), you don’t always get the people on the other end.” One respondent attributed this type of issue to a “time zone problem” in that synchronous connections such as videoconferencing potentially crossed numerous time zones precluding ease in arranging virtual face-to-face meetings with peers. In an instance in which the interviewer asked, “how does that feel when it (the computer) gets stuck?” a child responded, “I want to be mad at it.” Similarly, a health care provider stated, “The biggest (challenge) is consistency with working the computer games. Often (a window with a picture of) a dog comes up and says that they’re unable to locate their site or for safety purposes it’s been blocked. And a lot of the time they go to put on a game and they can’t get it to work. So that gets frustrating....” Beyond difficulties with software function, computer maintenance and the prevention of vandalism were issues of concern to health care providers. Accordingly, an important health care provider consideration was the balance of optimizing accessibility to the network (Nicholas et al., 2007)	

	Theme: Accessibility	
	Providing diabetes education in a simple, albeit engaging format (with visually appealing graphics and fonts) targeted for adolescents appears to be acceptable to adolescents as they transition to more autonomous diabetes self-management....However, many participants indicated that they did like the phone calls because of the personalized attention they received from the caller. Comparison of an automated text message delivery system versus personalized phone calls may aid in determining which delivery system is most effective and convenient for the participants. (Jaser et al., 2014) Parents and mentors agreed that the instruction prior to the initial support group session helped enhance the accessibility of the intervention. (Stewart et al., 2013a)	

		Theme: Accessibility		
Role of facilitator: ensuring relevance	It was also important for clinicians to learn ways to acknowledge other issues of concern that could be weaved into the BIFI-A intervention while still remaining focused on the goals of BIFI-A. (Gan et al., 2010) Prior to camp, adult staff adjusted programming plans to accommodate the needs of campers. Staff planned activities to be age appropriate (i.e., older campers engaged in more complex activities), to account for fatigue issues associated with HIV/AIDS and the heat of late July in the southern United States, and to maintain high counselor–camper ratios (Gillard et al., 2011) Through instrumental play and improvisations, those unable to verbally engage (e.g., preverbal, unable to speak English) can interact with someone other than their family. (O’Callaghan et al., 2013) Parents acknowledged that the children gained information, but also noted that their children’s confidence and empowerment was enhanced by interactions with peer mentors who helped make information relevant to their needs (Stewart et al., 2013a) Therapists may facilitate a therapeutic environment wherein withdrawn children can experience a musical “feeling memory” triggered by a familiar song or instrument. This can be a “key” for	“The exercise physiologist would work with you personally to make sure you were comfortable with where you were...make sure the exercise wasn't too easy or too hard.” (Kashikar-Zuck et al., 2016) More recently, as the ChIPS Reference Group has become more established, coordinators have identified young people who they think would benefit from participating in the Introductory Program. For example, co-ordinator 4 told us: Co-ordinator 4: “I scour [the hospital database] and see who’s in [hospital] and who might be a good candidate, ….Ah, ok, so we take anyone from 12 and up …we don’t take eating disorder patients because they have a different set of needs to chronically ill kids and you can see that divide just on the ward. So, our Crohn’s patients and our transplant patients and everything.” (Lewis et al., 2016)	Gan et al., 2010, Gillard et al., 2011, Kashikar-Zuck et al., 2016, Lewis et al., 2016, O’Callaghan et al., 2013, Stewart et al., 2013a, Whittemore et al. 2010, Wolf-Bordonaro, 2003, Wright et al., 2004,	Under engagement.

	Theme: Accessibility	
	supporting the child’s transition into engaging with the therapist and wider hospital environment (see Table 3). (O’Callaghan et al., 2013) Mentors believed exchanges between children and mentors made information personally relevant to the children. (Stewart et al., 2013a) The TEENCOPE Internet program included a health professional (a clinical psychologist) as the moderator who contributed to the conversations in the discussion board to stimulate discussion, provide feedback, and provide suggestions for problem solving. (Whittemore et al. 2010) If artists in residence or volunteers were part of a hospital’s arts in medicine program, supervision by a trained art therapist would be crucial in the planning of interventions to meet individual patient’s psychosocial needs, address individual differences, and tackle ethical issues that would arise. (Wolf-Bordonaro, 2003) This is why program leaders must come back to the basic value orientation of the PSRM. It is essential to view each child as an individual, which is the key to making the PSRM levels relevant to him or her. This is the case whether working with underserved youth or children with disabilities. The responsibility levels must be applied with sensitivity and flexibility	

	Theme: Accessibility	
	rather than rigidly imposed upon the participants (Wright et al., 2004)	

Theme: Accessibility				
Skills/training of staff to ensure accessible	The importance of training for mentors prior to commencement of activities: This kind of training addresses two content worlds. The first is the mentors' coping with diabetes (spiritually, emotionally, physically, and socially) in the present and past—a discussion that can help the mentors appreciate the knowledge they have in the present, and to empathically relate to the mentees. The second content world is the mentoring relationship—how to form it, its aims, expectations of the relationship, and managing it. It is important to underscore the importance of managing the relationship fluidly and flexibly in accordance with the adolescents' developmental needs. (Barnetz et al., 2012) There were several data bits that indicated that the BOC Program might not be operating as intended based on lack of staff participation or understanding of how the beads are to be given. (Baruch, 2012) they were not as intimidating as expected. The therapist's personality and interpersonal skills were important here (Dennison et al., 2010) This finding has important implications when training camp volunteers and staff. (Desai et al., 2014) the trainers' ability to modify the exercises to participants' baseline	"The physiology stuff at the beginning I didn't find helpful because I don't think it was fully explained, cause to be honest I don't think they fully understand it themselves" (YP5). (Reme et al., 2013) "As well, participants described how other parents should try not to worry because their children will be in capable hands with ''people who can take care of them if anything was to go wrong'' (White, 16)	Barnetz et al., 2012, Baruch, 2012, Dennison et al., 2010, Desai et al., 2014, Kashikar-Zuck et al., 2016, Reme et al., 2013, White et al., 2016/2014,	Overlap availability

Theme: Accessibility		
	abilities; (Kashikar-Zuck et al., 2016) Some found the teaching confusing and incomplete and not well organised. (Reme et al., 2013) Since Camp Oki is operated by the Hospital for Sick Children, caregivers felt comfortable and confident leaving their child for a week. Caregivers perceived that their children would be surrounded by doctors, nurses, and staff who would be familiar with their child’s medications, be aware of the signs and symptoms of a cardiac episode, and not restrict them from participating in daily camp activities (White, 14)	

Theme: Accessibility			
Intervention unable to address every need	Despite this positivity, a common theme was that the therapy was somehow incomplete and failed to tackle all aspects of the illness. ‘Psychological’ and emotional aspects appeared to be one area perceived to be ineffectively addressed. ‘It got us only so far, it was slightly limited. It was a little bit narrow in that it focused on one thing, but didn’t look at all the other factors’ (P 5 2 CBT). Participants described trying other treatments post-therapy (psychological and non-psychological), typically finding these useful in different ways and for different aspects of the illness, but usually complementary to the therapy received. Sometimes other life changes were deemed necessary for further improvement; personal growth, learning, or maturity were mentioned as important factors. (Dennison et al., 2010) The BIFI-A is not designed to replace other therapies or interventions that might be helpful. (Gan et al., 2010) This study suggests that online support groups supplement professional support, (Kirk et al., 2016) Participants were informed at the beginning of the program that these health-related Internet interventions were not a substitution for ongoing medical and/or psychological care, and participants were reminded to discuss		Dennison et al., 2010, Gan et al., 2010, Kirk et al., 2016, Stewart et al., 2013a, Whittemore et al. 2010

Theme: Accessibility			
	questions and issues with their parents and healthcare providers. (Whittemore et al. 2010)		
Social element makes "therapeutic" element accessible		“Actually, it wasn’t. And that’s good. I thought about everybody talking about their kids would be kind of depressing, but it turned out, the artwork and everything kind of opened everybody up.” (Brodeur, 2005)	Brodeur, 2005, O’Callaghan et al., 2012
Theme: Engagement			

Theme: Engagement

Idea for further interpretation/ Third Order Construct	Second Order Construct	Quote	Papers contributing	Acknowledgement of overlap
Engaging at level to meet own needs with no formal adaption required	We gained the impression that characteristics such as gender and economic status also influenced the development of the relationship patterns to a certain extent. Most of the soul mate relationships developed between women mentors and mentees. This may be because heart-to-heart talks are more typical of communication between women. Additionally, the social worker pattern almost always occurred with mentees from a low economic status, and in a considerable proportion of cases, it seemed that parents expected the mentors to help in the mediation between them and the medical services treating the mentees. (Barnetz et al., 2012) Members of planning committees also have wondered about the value and feasibility of offering formal group discussions at camp about cancer and the effects of realmet. This does not seem warranted, however, because the children were able to find opportunities to exchange information, thoughts, feelings, and attitudes in the context of every-day camp activities (Bluebond-Langer et al., 1991-Langner		Barnetz et al., 2012, Bluebond-Langer et al., 1991, Gillard et al., 2016/2011, Kirk et al., 2016, Nicholas, Shrimpton et al., 2013,	

Theme: Engagement		
	et al., 1990) (Bluebond-Langer et al., 1991) According to a Teen Talk facilitator, the most effective locations for group dynamics and learning were those where individuals in the group could hang back and observe if they wished. It was important for campers to be able to hide their emotions within the larger group if they needed to, because “[i]t be real deep at Teen Talk” (Gillard et al., 2011) Sense of belonging refers to relationships that were cultivated and maintained throughout the camp session. Sense of belonging was the most identified theme, with 21 of the 24 campers commenting. Those 21 campers commented on sense of belonging 38 different times throughout their video recordings. Sense of belonging can be understood as the sensation of being connected and accepted by one's family, friends, and community (Kitchen, Williams, & Chowhan, 2012). This theme was most prevalent among campers with cancer and HIV/AIDS. (Gillard et al., 2016) Other individuals appeared to post messages only when they were experiencing a particular problem and did not engage in providing support to others.(Kirk et al., 2016) Age, developmental stage and personal	

Theme: Engagement			
	interests appeared to have an impact on how the network was used by participating children. Reflecting typical developmental processes, younger children favored individual-oriented activities whereas older children and adolescents more frequently engaged in dyadic or group-based activities. Children under 10 years of age tended to engage in solitary activities such as playing online games more frequently than interacting or chatting with peers. For these younger children, the network was often seen as, in one parent’s words, a “distraction tool and entertainment.”...Online resources provided children with the opportunity to chat about their illness and engage in discussion as much or little as they desired. (Nicholas et al., 2007) An important aspect of this finding was that the nature and degree of distraction generated by the MMP appeared to vary among different patients according to their needs. For example, for children who did not find radiotherapy stressful, participating in the MMP helped to (Shrimpton et al., 2013)		
Range of different expectations prior to intervention	Expectations about the extent to which the therapy might be beneficial varied widely (Dennison et al., 2010)	The experiences and opinions of others had a large influence on the young people’s decision to do the	Dennison et al., 2010, 2010; Reme et al.,

	Theme: Engagement		
	most participants, the ideas and practices of meditation and yoga were quite new, and many came into the course thinking that such methods were ‘‘strange’’ or ‘‘weird’’ or that the methods presented would simply be ‘‘boring.’’ (Sibinga et al., 2011)	Lightning Process. “I was expecting what happened to my friend, which was that she Fair et al., 2012ly quickly was able to start doing all the things she had not been able to do” (Reme et al., 2013)	2013, 2013; Sibinga et al., 2011, 2011

Theme: Engagement				
Reminders: calls/texts (both needed and received)	They had difficulty in understanding and remembering the verbal information received. (Barlow et al., 1999) and providing reminders for family members and AYAs to bring in pictures from home. (Burns et al., 2010) yet all felt that the handouts and articles were useful to keep as a reference.(Gan et al., 2010) Parents reported that delivering positive affirmations to adolescents was ‘‘special’’; as one parent reported, ‘‘I liked reminders to say something nice. It was an opportunity to bring out dialogue.’’...Two adolescents reported that they only used the PA exercises when reminded, otherwise they ‘‘forgot about it,’’(Jaser et al., 2014) I need some sort of a plan. So this was helpful how it is always scheduled same day, same time. I get the concept but I forget the positioning exactly. (Kashikar-Zuck et al., 2016) families identified potential barriers to using the Cellie Kit: soft toy limitations during parts of treatment (e.g., bone marrow transplant), remembering to bring the Cellie Kit to the clinic/hospital, concerns about seeing “my child has cancer”, and the possibility that some children would not bond to the Cellie toy. (Marsac et	‘‘I liked the CD best. I get really stressed out coming home from school and helps me to remember’’ (Bignall et al., 2015) For instance, a child had difficulty remembering his online password: “You would need a password to log in and I forgot mine....”A parent described system difficulties with the computer: “Sometimes (the ill child) gets a bit frustrated...because (the computer) freezes.” (Nicholas et al., 2007)	Barlow et al., 1999, Bignall et al., 2015, Burns et al., 2010, Gan et al., 2010, Jaser et al., 2014, Kashikar-Zuck et al., 2016, Marsac et al., 2012, Nicholas et al., 2007, Whittemore et al. 2010	Integrating into daily life

Theme: Engagement	
	al., 2012) As with in-person interventions, reminder systems are often critical to optimize attendance. In this study, automated e-mails were generated when new sessions were posted; however, approximately 50% of participants also required reminder telephone calls to complete sessions...Other investigators evaluating health-related Internet interventions have also reported the need for developing an effective reminder system to promote the completion of sessions or tasks associated with the intervention.39 (Whittemore et al. 2010)

Theme: Engagement			
Role of facilitator in emphasising awareness/relevance	Parents and guardians reported few concerns. Most had long-standing relationships with the social worker who first introduced the idea of a creative writing group. (Fair et al., 2012) The findings suggest several implications for practice. First, children and youth services professionals and others should consider recommending a medically-supported summer camp to eligible adolescent patients. (Gillard et al., 2016) Clearly, social workers, child life specialists and other health care professionals play an important role in informing children and adolescents about the network. (Nicholas)	"I scour [the hospital database] and see who's in [hospital] and who might be a good candidate, and so…" (Lewis et al., 2016)	Fair et al., 2012, Gillard et al., 2016, Lewis et al., 2016, Nicholas et al., 2007

Theme: Engagement			
Explaining rationale to improve engagement	Second, children and youth services professionals can use the findings from this study to tailor their discussions about camp to adolescents with different serious illnesses. Specifically, given that many youth with HIV/AIDS and sickle cell disease are hesitant to share their illnesses with others and thus tend to feel isolated, camp can be offered as an opportunity to experience a place to "be themselves." For adolescents with cancer and HIV/ AIDS, camp can be positioned as a place to belong and an escape from disease-related fears and tribulations. For adolescents with sickle cell disease, the recreational aspects of camp can be emphasized. For adolescents with metabolic diseases, camp can be positioned as offering opportunities for positive affect. (Gillard et al., 2016) Some participants highlighted the development of a shared theoretical rationale for CFS as a helpful aspect of the Lightning Process, whilst also expressing frustration at those who did not fully understand it. (Reme et al., 2013)	"The explaining of the process, the background information definitely helped because it helps you realize how the process works, and there is no point doing something unless you understand how it works… otherwise you won't believe in it enough" (Reme et al., 2013)	Gillard et al., 2016, Reme et al., 2013

Theme: Engagement			
Evidence behind interventions validating/reassuring		Parents engaged with the Cellie Kit on a more intellectual level, appreciating its evidence-based materials. For example, in study 1 (Cellie Kit comments), one parent stated, “This would be a very good tool. (This has) techniques developed through research with other families and (would be) very beneficial.” (Marsac et al., 2012)	Marsac et al., 2012
Expectations matching experience affecting views on effectiveness	The last negative aspect that was mentioned was the dishonesty the staff showed when they claimed the treatment had a 100% success rate. ‘I think the people that run it say they have 100% success rate, but obviously that is not true, and I just think that the way they go about it is awful, blaming people that if it doesn’t work then, you know, it’s your own fault. I think that is absolutely awful’. (Reme et al., 2013)		Reme et al., 2013
Not knowing anyone	While most children enjoyed online dialogue with peers, a few children described discomfort in forging relationships with unknown persons and discussing personal health details in online interaction. (Nicholas et al., 2007)	“Right at the beginning when I hadn’t met anybody and didn’t know where I was going and all those kinds of things, ummm, being quite young, being very ill, very worried. And I personally wouldn’t have coped very well if they had just invited me to go to somewhere. I needed my mum there” (YP 7 2 PE). (Dennison et al., 2010) Related to worries over meeting new people, one female stated,	Dennison et al., 2010, Fair et al., 2012, Nicholas et al., 2007,

Theme: Engagement			
		“I was all shaky and stuff because I didn’t know nobody.” (Fair et al., 2012)	
Worries affecting engagement	a few described prior hostility to participating. (Dennison et al., 2010) A health care provider conveyed rare concern about children connecting with peers who were not previously known: It’s hard. They (the children) get shy, you know, especially (when the child is)... unfamiliar with the concept of a chat. And when they are (familiar), it’s usually chatting with their friends . . . Then you put them in a chat room, with a ton of people that they don’t know, and all of a sudden they’re faced with trying to make conversation with strangers. It’s not so easy, especially when sometimes the (others) . . . want to talk about their illness ...,and (the local ill child) doesn’t at all. (Nicholas et al., 2007) Those adolescents who decided not to hold someone's hand gave reasons such as fear of hurting the person's hand, unavailability of the preferred person (usually mother), or that no one offered then a hand to hold and they	“Right at the beginning when I hadn’t met anybody and didn’t know where I was going and all those kinds of things, ummm, being quite young, being very ill, very worried. And I personally wouldn’t have coped very well if they had just invited me to go to somewhere. I needed my mum there” (Dennison et al., 2010) It’s hard. They (the children) get shy, you know, especially (when the child is)... unfamiliar with the concept of a chat. And when they are (familiar), it’s usually chatting with their friends . . . Then you put them in a chat room, with a ton of people that they don’t know, and all of a sudden they’re faced with trying to make conversation with strangers. It’s not so easy, especially when sometimes the (others) . . . want to talk about their illness ...,and (the local ill child) doesn’t at all.(Nicholas et al., 2007)	Dennison et al., 2010, Nicholas et al., 2007 White, 2014, Weekes et al., 1993

	Theme: Engagement	
	were embarrassed to ask (Weeks) Participants also expressed that they did not have the same fears that they would normally exhibit if their child would be attending another camp. Judy suggests that: [laughs] Yeah if it was any other camp I don’t think I would send him away by himself for a whole week. But simply because it’s SickKids and we’re grateful for SickKids and it will be run by a medical team – that was enough for us. (White, 2014)	

	Theme: Engagement		
Fear of stigma/leaking of diagnosis	While most children enjoyed online dialogue with peers, a few children described discomfort in forging relationships with unknown persons and discussing personal health details in online interaction. (Nicholas et al., 2007)	One discussed having to cope with negativity from some members of her local patient support group when she decided to attend therapy. “We were getting, my parents as well, were getting flack from some quarters and we felt like we had betrayed the ME cause by trying to make something that would make my life easier” (Dennison et al., 2010) “My biggest fear is telling the wrong person and then being exposed in front of people.” (p. 15). “My biggest fear is not being accepted for my disease, as well as my disability, especially” (p. 19). Even when participants did not identify specific concerns, they noted that other members were worried about possible disclosure. For example, one adolescent said, “I wasn’t worried. [but] other people were worried about their names getting out.” (Fair et al., 2012)	Dennison et al., 2010, Fair et al., 2012, Nicholas et al., 2007, Griffiths
Concerns dissipating over course of intervention	The camp did help with that [to talk about our different experiences] by bringing us all together and letting us get to know each other for a couple of days so that we felt that we were comfortable enough to go up to each other and just talk about it (CFDs). (Tiemans et al., 2007)		Tiemans et al., 2007

	Theme: Engagement	
Toleration of discomfort/frustration	Children were aware that this knowledge might hinder their initial adjustment, but felt that by knowing ‘everything’, the unpredictable nature of JCA would be easier to cope with in the long term and unexpected setbacks would be less traumatic. (Barlow et al., 1999) Adolescents assured future participants that the group would be rewarding, despite potential discomfort at first. (Fair et al., 2012) No safety issues were reported or adverse effects other than the expected temporary muscle soreness after initiating new exercises. (Kashikar-Zuck et al., 2016) A parent described system difficulties with the computer: “Sometimes (the ill child) gets a bit frustrated...because (the computer) freezes. (Nicholas et al., 2007) For subject 1 in particular, liberation from carefully guarded defenses was accompanied by a temporary amplification of emotional vulnerability. The incongruous data point during the intervention phase of the ABS mark this transition from highly defended to psychologically supported. (Wolf-Bordonaro, 2003)	Barlow et al., 1999, Fair et al., 2012, Kashikar-Zuck et al., 2016, Nicholas et al., 2007, Wolf-Bordonaro, 2003

Theme: Engagement				
Time to develop relationships with peers (references indicate time too short)	Furthermore, the direct and ongoing encounter with the mentors over a year enables the mentees to learn about many things they do not dare ask about, or even problems they were previously unaware of. (Barnetz et al., 2012) Recently, members of camp-planning committees have raised the following question: Should camp be extended beyond the 7-to-14-day sessions presently offered (Bluebond-Langer et al., 1991) Our study results show that the participants’ value of camp experience to children with heart defects 559 narratives about the meaning of the weekend camping experience agreed with prior research from lengthier camping sessions regarding the benefits of camping (Desai et al., 2014) Further opportunities for forming caring connections could include increased time to share concerns and information, ways for campers to discover similarities with other campers, and engaging in fun recreation activities that make these other goals palpable to youth (Gillard et al., 2011) Indeed, the full benefit of ChIPS participation is unlikely to be experienced during the 8 week Introductory Program, but to		Barnetz et al., 2012, Bluebond-Langer et al., 1991, Desai et al., 2014, Gillard et al., 2011, Lewis et al., 2016, Moola et al., 2015, Tiemans et al., 2007	Opportunities to develop connections: Safe space

Theme: Engagement	
	accumulate with ongoing participation. (Lewis et al., 2016) Temporal relations also featured centrally in CHD youths’ camp experiences. The participants’ main complaint about Camp Willowood is that its one-week duration is ‘too short’, compromising the formation of long-lasting friendships.(Moola et al., 2015) Participants also reported wanting more time together to develop mutual trust and identify issues of concern (Tiemans et al., 2007)

Theme: Engagement				
Fun facilitating initial engagement/interactive activities	This is a relationship in which the principal, dominant element is fun and enjoyment of the pleasurable and out of the ordinary activities in which both mentor and mentee participate. The impression we gained was that when the recreational partner pattern was dominant, the meetings were experienced by mentees as very enjoyable, and great emphasis was placed on the content of the activity (Barnetz et al., 2012) When the children were asked, "Why do you want to go to camp?' their immediate response was "to have a good time.' (Bluebond-Langer et al., 1991 Langer) didn't know it was going to have all this fun stuff to do, like that thing with the beads. R: What were some of the things that you liked about the program? P: The people and the stuff. I liked some stuff that we did. R: What did you like that you did? P: I liked the balloon gam (Brodeur, 2005) and a stimulating fun space (Campbell et al., 2010) Having fun Feeling unified/not the only one with a heart defect (Desai et al., 2014) The participants enjoyed painting and often used acrylic paint and canvasses	"I had a lot of fun. I liked it when we all went off to our own counseling groups, 'cause you got to talk to kids your age and how they felt. I liked the artwork too; that Was fun.,"pg. 4 (Brodeur, 2005) Thirteen of the children described the camp experience as just being ''fun.'' This fun is summed up in one child's description, ''I would say it's fun. You get to do a lot of activities. Being in nature you have fun. You have fun campers. You have fun counselors.'' (Bultas et al., 2015) "We had fun and did funny things" [teen 7]. (Gan et al., 2010) The meaning of camp in my life is just fun. It's just a fun place to go and like, there's a lot of people here that love you and like you can (Gillard et al., 2016) There was a strong ethic of focus on the enjoyment of campers. In staff training, a director determinedly stated, "We're here for the campers. Our job is to focus on campers. If you do that, at end of week, you will say you had a great experience. This week is supposed to be the best week of these kids' lives." A health care staff member explained why this ethic was so important: "Camp is often sometimes the last experience a	Barnetz et al., 2012, Bluebond-Langer et al., 1991, Brodeur, 2005, Bultas et al., 2015, Campbell et al., 2010, Desai et al., 2014, Fair et al., 2012, Gan et al., 2010, Gillard et al., 2011/13/16, Hosek et al., 2012, Nicholas et al., 2007, O'Callaghan et al., 2013, Shrimpton et al., 2013, Stewart et al., 2013a, White Whittemore et al. 2010, Wolf-Bordonaro, 2003, Wright et al., 2004, 14,	Fun: Unconstrained

Theme: Engagement		
	to tell stories, respond to the day’s activities, or simply to have fun with color. (Fair et al., 2012) Youth spoke at length about their enjoyment of the fun activities at camp. Activities were fun because they were exciting, relaxing, novel, or interesting.(Gillard et al., 2011) The habitat of fun consisted of abundance and opportunities for transgressions, which were grounded in an unceasing focus on campers' enjoyment and engagement. As a Junior Counselor explained I think [this camp is] unique because you're in a setting with so many kids, and you're in a setting where you're scheduled to have fun constantly and you don't have as much down time as at home, so it creates a habitat of fun and constantly going that you don't get anywhere else.(Gillard et al., 2013) Some children specifically became interested in network utilization as a result of the prospect of accessing games that were perceived as “fun. (Nicholas et al., 2007) Finally, and perhaps most importantly, music therapy can enable creativity, play, fun, and laughter, the value of which is incalculable, especially when a child’s cancer becomes life-limiting (O'Callaghan13) Meanwhile, the MMP-assisted children	kid's gonna have before they lose the fight. So, one of the better places to be at (besides with your family) is to create new friends and experiences before that day comes.” (Gillard et al., 2013) “I really like exploring new things – I really like going in the woods and exploring them a lot and it was really fun.”(Moola et al., 2015) Well, I like pretty much everything I like. I like the way how it’s set up. I like a lot of it! I like pretty much everything! Like I liked how we had a big conversation about everything and then we answered questions and everything and looked at stuff that was actually fun and then we. . . after went to Club Penguin. I really liked it. (8-year-old boy with asthma and allergies) (Stewart et al., 2013a)

Theme: Engagement		
	who were frightened of radiotherapy to redirect their attention to movie planning and production tasks (eg, discussing storylines, choosing music and filming and editing footage) that were viewed as ‘exciting’ and ‘fun’. (Shrimpton et al., 2013) All caregivers anticipated that their children would have a fun and wonderful time while away at camp, (White, 2014) Teenagers who disliked the site felt that it was more appropriate for adults and needed to be more interactive. (Whittemore et al. 2010) None of the subjects resisted participation in the study, and all eagerly participated in the art making process. (Wolf-Bordonaro, 2003) They noted that the martial arts program would probably be more fun for children than traditional therapy. Both felt this would provide a motivating factor not present in the traditional therapeutic setting. (Wright et al., 2004)	

Theme: Engagement				
Incentives/Memento/share with others	The participating children and parents describe the BOC Program as providing them with a way to communicate with others and to help them "remember" their treatment experience.(Baruch, 2012) The AYAs had a sense of purpose to the day, and hope: "It was a project that we all focused on; it gave us all something to contribute to, and it's a wonderful remember (Burns et al., 2010) Receiving lunch and vouchers encouraged attendance (Campbell et al., 2010) Most campers discussed in detail how they reflected on and looked forward to opportunities for reprieve and recreation all year. One camper told another camper, "This is the most fun I have all year." The activities of anticipation and reflection were supported through camp mementos such as a memory book, diplomas, certificates, awards, and gifts from counselors.(Gillard et al., 2011) At camp, it was evident that participants (campers and counselors) felt connected to a phenomenon with a past and a future. For example, a camp volunteer created a DVD film of the previous year that camp administrators and volunteers gave to potential and past participants, and showed on the	"Okay. Was Living Well what you thought it was going to be? It was better. It was better? P: Mmm-hmm. R: Right on. What was better about it? P: It had free food. I didn't think there was going to be any food there." (Brodeur, 2005)	Baruch, 2012, Brodeur, 2005, Burns et al., 2010, Campbell et al., 2010, Gillard et al., 2011, Gillard et al., 2013, Griffiths, Jaser et al., 2014	

Theme: Engagement		
	first night of camp. (Gillard et al., 2013) By using exercises in gratitude and self-affirmation, small gifts, and parent affirmations, we attempted to boost adolescents’ PA, thereby increasing their motivation for diabetes management. (Jaser et al., 2014)	

Theme: Engagement			
Something new	For all young people, this approach was novel. Activity had previously been on an all-or-nothing basis; bursts of over-exertion or excessive rest. (Dennison et al., 2010) The novelty of the cabin living experience, combined with the opportunity to engage in activities, and nurture their relationships with each other, seemed to be meaningful for them.(Desai et al., 2014) Youth engaged in physical activities they could not do at home due to cancer treatments and real or perceived limitations based on illness placed on youth by their caregivers. Engaging in new and fun activities connected to feelings of freedom. (Gillard et al., 2013) prevalent among campers with HIV/AIDS. The pool was frequently cited as one aspect of camp programming that emerged as a meaningful experience for camper study participants. One camper said that one of the things he wanted to take from camp was “the pool area because that's something that you don't find everywhere.(Gillard et al., 2016) One adolescent, however, expressed that the information in the education packets ‘‘was not new.’’ (Jaser et al., 2014)		Dennison et al., 2010, Desai et al., 2014, Gillard et al., 2016/13, Jaser et al., 2014, Kashikar-Zuck et al., 2016, Marsac et al., 2012, Moola et al., 2015, Nicholas, White, 2014, Wright et al., 2004

	Theme: Engagement	
	They exercises were different every two weeks... (Kashikar-Zuck et al., 2016) In study 2 (pilot intervention feedback), most families reported learning new information and/or skills from using the Cellie Kit. (Marsac et al., 2012) Some patients reside in small towns that are located several hundred kilometres from major city centres, and had never interacted with another CHD child. For these participants in particular, the experience of ‘being the same’ was a novel one. (Moola et al., 2015) The network offered social connection, provided new opportunities and learning, and increased exposure to peers who lived with similar daily realities. (Nicholas et al., 2007) The majority of caregivers discussed how camp would offer their children the opportunity to experience new recreational activities. Like most participants, Henry comments on his son’s ability to acquire new physical skills, “I think it’s about – certainly canoeing, kayaking, archery – all those things that he’s never experienced before. (White, 2014) Brandon’s mother said, “It’s important, the more variety of therapy he gets, the more well-rounded his treatment	

	Theme: Engagement	
	is. The broader the treatment program is, the more beneficial it is. And it’s something he enjoys. It’s hard to refuse bringing him when he enjoys it. It’s good for him.” (Wright et al., 2004)	

Theme: Engagement			
Interesting graphics	Providing diabetes education in a simple, albeit engaging format (with visually appealing graphics and fonts) targeted for adolescents appears to be acceptable to adolescents as they transition to more autonomous diabetes self-management. (Jaser et al., 2014) The Managing Diabetes site was revised to have greater visual appeal by decreasing text and increasing pictures of diverse teenagers. (Whittemore et al. 2010)		Jaser et al., 2014, Nicholas 12, Stinson 2008; 2010, Whittemore et al. 2010
Theme: Keeping It Going			

Theme: Keeping It Going

Idea for further interpretation/ Third Order Construct	Second Order Construct	Quote	Papers contributing	Acknowledgement of overlap
Evidence based framework/manual	It was hypothesized that children and clinicians would mutually benefit from the program as a prescriptive-nursing intervention to deliver a form narrative medicine. (Baruch, 2012) The final product is the BIFI-A, a structured family system intervention for adolescents with ABI, which encompasses a broad curriculum across a 12-session format. The intervention has been manualized to provide guidance to clinicians around implementation (Gan et al., 2010) We are therefore conducting initial rigorous testing of the FIT Teens intervention as a "proof-of-concept" to develop the manualized protocol which can then be delivered in community settings where physical therapists and trainers are more readily available and can be easily trained in the protocol. (Kashikar-Zuck et al., 2016)		Baruch, 2012, Gan et al., 2010, Kashikar-Zuck et al., 2016	

Theme: Keeping It Going				
Training/ongoing supervision	The importance of training for mentors prior to commencement of activities: This kind of training addresses two content worlds. The first is the mentors' coping with diabetes (spiritually, emotionally, physically, and socially) in the present and past—a discussion that can help the mentors appreciate the knowledge they have in the present, and to empathically relate to the mentees. The second content world is the mentoring relationship—how to form it, its aims, expectations of the relationship, and managing it. It is important to underscore the importance of managing the relationship fluidly and flexibly in accordance with the adolescents' developmental needs...The importance of ongoing guidance for mentors: Ongoing guidance in the form of regular group meetings, as well as having someone available for consultation in real time, is essential for maximizing the benefits of the mentor–mentee relationship and resolving problems that arise during the process. In this kind of guidance it is important to encourage mentors to provide their mentees with opportunities to deepen the relationship from a belief in the mentees' abilities to take advantage of	"And then there's the risk that a kid starts to write something that maybe puts them in a precarious situation that we have to address in the class. We didn't know what was going to come out, what kids were going to write, what they were going to say." (Fair et al., 2012)	Barnetz et al., 2012, Baruch, 2012, Desai et al., 2014, Fair et al., 2012, Gan et al., 2010, Gillard et al., 2011, Gillard et al., 2013, Stewart et al., 2013a, Wolf-Bordonaro, 2003	Resources (Trained staff): Availability

	Theme: Keeping It Going	
	the learning opportunities presented to them in accordance with their needs and qualities (Barnetz et al., 2012) There were several data bits that indicated that the BOC Program might not be operating as intended based on lack of staff participation or understanding of how the beads are to be given. (Baruch, 2012) Under-appreciated in the literature is campers' relationship with counsellors who participate along with them in activities, encourage them to push their limits, and facilitate interactions among camp peers. Our research adds to the literature by supporting an earlier study which documented that supportive staff–camper interaction is an important process at camp which allows campers to establish meaningful relationships (Gillard et al. 2011). This finding has important implications when training camp volunteers and staff. (Desai et al., 2014) Finally, as noted earlier, the group leaders were not qualified to do formal group therapy. However, the findings are illustrative of the therapeutic benefits of creative writing groups for youth with HIV. Creative writing groups appear to	

Theme: Keeping It Going		
	have potential as a clinical tool in the hands of qualified therapists. (Fair et al., 2012)test clinicians stressed the importance of having training in family counselling, experience with ABI and adolescents and access to peer consultation for clinical support around complex family situations.(Gan et al., 2010, 2010) Facilitators were seen as people who were approachable because of their extensive experience providing “raw” HIV/AIDS education to youth...It appeared that some counselors were unprepared to deal with specific issues such as behavioral problems, incidents of sadness or grieving, and disagreements...Camp staff expected and planned for anger management problems to arise at camp because of these issues...peers frequently mentioned issues around disclosure of HIV status to other people, though counselors seemed less aware that this was a major issue in campers’ lives...Opportunities for campers to form caring connections can be planned for in every domain of camp, especially through staff selection and training procedures, establishment of ground rules in educational sessions like Teen Talk, within cabins and during activities, and outside of camp. (Gillard et al., 2011)	

	Theme: Keeping It Going	
	Camp administrators are urged to strategically plan for opportunities for campers to share concerns and issues about cancer by training counselors to facilitate the discussions...discussions emerged, yet some counselors appeared to feel ill-equipped to handle these out-of-the-blue questions and discussions (Gillard et al., 2013) Peer mentors reported that their training by researchers and the support they received from health professional partners were critical factors in ultimately meeting the support needs of the children (Stewart et al., 2013a) If artists in residence or volunteers were part of a hospital’s arts in medicine program, supervision by a trained art therapist would be crucial in the planning of interventions to meet individual patient’s psychosocial needs, address individual differences, and tackle ethical issues that would arise. (Wolf-Bordonaro, 2003)	

Theme: Keeping It Going				
Resources	Parents thought familiarity with staff members improved children’s feelings of trust and security which, if it is the case, highlights the importance of employing permanent members of staff that children can get to know which may promote child coping. (Ayres et al., 2011) There are no easy solutions to the issues raised by children and their parents, since the feasibility and cost-effectiveness of producing high-quality psycho-educational interventions can often prohibit tailored approaches and widespread dissemination. (Barlow et al., 1999) Understanding the perspectives of children with CHD regarding how they value and derive benefit from a therapeutic weekend camping programme is vital for planning services to optimize beneficial outcomes. These findings are important given the current scarcity of resources (financial, time, and personnel) when funding for summer camps of longer duration may be reduced. (Desai et al., 2014) This low-cost intervention is easily replicated in low-resource areas (Fair et al., 2012) Given the current healthcare climate of limited resources and long waiting lists for service, it is imperative that	“I worry. I worry about Living Well because I worry that they’re not going to get funded because there might not be a huge change in someone, but when you’re chronically ill, you don’t need a huge change to make a difference; you just need a little change. And I think whoever grants you all the money needs to know that. You might not see a huge change after each session, but there’s change. Does that make sense? And I worry about that” (Broduer) A counselor explained how the equipment and facilities promoted participation, which contrasted to campers feeling constrained at home: “They make the wall so everybody can do it, they make sure everybody can get in the pool, everybody can participate…They have special bikes everybody can use.” (Gillard et al., 2013) (The ill child) would say to me, “oh Mom, look at that beautiful playroom and I can’t even go.” And at one point there was (another child) across the hall from her and they wanted to talk so bad, but they couldn’t because they both had different bugs ...If they had a computer, between them, they could have had a great time. So,	Ayres et al., 2011, Barlow et al., 1999, Brodeur, 2005, Desai et al., 2014, Fair et al., 2012, Gan et al., 2010, Gillard et al., 2013, Jaser et al., 2014, Marsac et al., 2012, Nicholas et al., 2007, O’Callaghan et al., 2013, Shrimpton et al., 2013, Stewart et al., 2013a, Whittemore et al. 2010, Wolf-Bordonaro, 2003.	Availability: Staff training/resources to set up intervention

Theme: Keeping It Going			
	interventions be efficient, time limited and replicable to allow for evaluation of their efficacy. (Gan et al., 2010) Lastly, mailing the personalized small gifts was time consuming and required additional costs for postage and mailing supplies, and thus future studies could explore the use of e-gift cards as an alternative to personalized gifts, which could be used to purchase music or games to be played on electronic devices. (Jaser et al., 2014) Even within this highly supportive environment, families without an identified need found this tool helpful, suggesting a viable mechanism by which medical teams can supplement their care without requiring additional time commitments from providers. (Marsac et al., 2012) Participants described periodic barriers to accessing and utilizing the network. A logistical barrier was the finite number of computers within the hospital and, hence, limited locations to access the network. (Nicholas et al., 2007) Beyond difficulties with software function, computer maintenance and the prevention of vandalism were issues of concern to health care providers. Accordingly, an important health care provider consideration	I'm thinking down the road when computers are in every room, it will make kids' lives a lot more normal... Several participants similarly emphasized the need to ensure ongoing availability of network support for children, and several offered recommendations for increased accessibility. For instance, a parent recommended, "especially if (children) are in isolation . . . put (the network) on laptops and it (would) take a lot less space ...It would be more portable between rooms and we could take it to a lot more places." (Nicholas et al., 2007)	

	Theme: Keeping It Going	
	was the balance of optimizing accessibility to the network while Nicholas et al. 219 simultaneously ensuring the security and maintenance of the computers....Given the substantial workload demands, online networks appear promising as an augmenting source of psychosocial support... Offering effective and accessible child-centered resources constitute important elements for pediatric health care delivery. (Nicholas et al., 2007) Children who learn instruments before the diagnosis may continue to play in hospital, even when they have ceased lessons, and may use the music therapist’s support for this, for example, through playing duets or borrowing hospital instruments. (O’Callaghan et al., 2013) Like many psychosocial interventions, the MMP has a low resource base and to a large extent relies on the time donated by clinical staff. While our respondents admired this, five participants pointed out that it also impacted on programme delivery. For example, several said they had not been approached to take part in the MMP until their child was well into their RT treatment, and would have appreciated the ability to begin the	

Theme: Keeping It Going		
	programme earlier. ... Although these comments were not widespread, they nevertheless highlight the very obvious role of funding in effective programme delivery.26 With the MMP, the root cause of the issues identified by our interviewees was the lack of time that staff could provide to the... programme. Indeed, while novel programmes like the MMP can be valued by hospital administration for their contribution to supportive care, patient satisfaction with services and even for generating positive publicity, without appropriate funding they run the risk of becoming ad hoc activities, or, to end abruptly when key staff move on. A key challenge then for the MMP, and similar innovative psychosocial programmes, is to establish a secure funding base as without it sustainability is questionable, and the benefits to patients' risk being lost (Shrimpton et al., 2013) As Internet is available in many remote and rural settings (Murray et al., 2006; Nicholas et al., 2009) it is a useful tool for community- based nursing interventions regardless of location. The low cost and adaptability	

	Theme: Keeping It Going	
	of this online support intervention can be modified and replicated by nurses in diverse settings for children representing different ages and chronic conditions and tested through larger scale intervention trials. (Stewart et al., 2013a) Results from the various phases of designing the Internet sites also indicate that the development of Internet interventions is complex and time-consuming...Implementing health-related Internet interventions also requires sophisticated technological support and state-of-the-science programming to maintain functionality and security of the Internet sites. (Whittemore et al. 2010) For example, if a hospital initiated the availability of art therapy for its patients, physical space would be required to conduct art therapy, particularly, if family or group art therapy were initiated. The activity room described in this study would accommodate a small group, but not a large group or open studio. (Wolf-Bordonaro, 2003)	

Theme: Keeping It Going			
Emotional/Social Impact outside of setting	From the mentees' point of view, a large part of the learning and its effect was not necessarily achieved by in-depth discussions and emotional conversations but by observing the mentors and their behavior, and sometimes simply by the mentors' very presence, as one of the young people said: We didn't talk and we didn't have to. Before meeting the mentor I didn't do my blood test before lunch, now I do it, they tried to convince me it was important, I knew I should but I didn't do it, the mentor didn't have to persuade me, he just did it and that was that. (Barnetz et al., 2012) All participants' comments suggested that in the supportive group setting of camp, they felt more comfortable trying out new activities, practice skills, and build confidence which some carried over to a larger community context. (Desai et al., 2014) Adolescents unanimously reported increased confidence levels that were evident within the confines of the group, as well as in their everyday interactions.(Gillard et al., 2011) Camp also seemed to influence sociability outside of camp. A Junior Counselor reflected, "The following fall after camp I was more open about	One camper in particular addressed this issue by saying, "I would take the atmosphere of it because it just makes me feel really happy and during the school year when I'm kinda down and I don't have a happy place to go to I just look at my camp bracelets and all the memories that I have from the week and it just makes me so happy inside." (Gillard et al., 2016) "I: Which of the methods did you enjoy most? P: I'd say the breathing meditations. I think it was one, two, three. Like say if you was in a heated argument or an argument was about to start off, you breathe like take three breaths and then take it from there because I'm a big arguer. I like arguing. I don't like starting them, but hey, if they start, I must finish. So with that I have to do like a one, two, three, pause, breathe-type thing. I: How do you do that? P: For me, I've actually practiced it the other day. I was about to get in an argument. I just sat there and I took three breaths and did my own little counting in my head and took three more breaths. And I was actually calm and left the argument—just let it be." (Sibinga	Barnetz et al., 2012, Desai et al., 2014, Fair et al., 2012, Gillard et al., 2011, Gillard et al., 2013, Gillard et al., 2016, Kashikar-Zuck et al., 2016, Lewis et al., 2016, Nicholas et al., 2007, O'Callaghan et al., 2013, Shrimpton et al., 2013, Sibinga et al., 2011, Stewart et al., 2011b, Stewart et al., 2013a, White et al., 2016, White, 2014, Wolf-Bordonaro, 2003

Theme: Keeping It Going			
	things, I talked more, I guess I was louder, I made more friends when I went back to school. I guess I can thank camp for that.”. (Gillard et al., 2013) The mini-relaxation... is really quick, you can use it anytime. It's going to be helpful when I'm in class. (Kashikar-Zuck et al., 2016) Parents and ChIPS co-ordinators also spoke of observing the young people’s strength of character and the capacity for ChIPS to engender a buoyant, positive attitude that flowed into daily life. (Lewis et al., 2016) within their own lives, as exemplified by a child who became emotionally more able to receive injections following online information and interaction. (Nicholas et al., 2007) Music therapy sometimes prevents this need through being conducted via a closed-circuit TV (CCTV) screen in the treatment room: the child watches the therapist on a portable DVD player who sings previously selected songs and maintains contact as radiation is administered...Children have also composed and recorded music CDs with a therapist, which were then used to distract and provide a focus during radiation sessions (O’Callaghan et al., 2013)	et al., 2011) The teens learned strategies for communicating. “Certain things that I’ve talked about in the peer group, I’m talking about it more in my family; I’m not keeping things to myself” (Stewart et al., 2011b) “It’s going to be a growing experience for our family—to be able to let go and be able to allow him to be the child that in our hearts we know that he could be … Oh it will be a wonderful feeling knowing that he has accomplished things that we never thought he would be able to accomplish either. So it would be a great feeling for our family that, ‘hey you know what, now we know that this is something he enjoys, we should get him involved in it or look where else we can do it’.” (White et al., 2016) Participants anticipated that the new behaviours they would exhibit following camp would transition into their daily living...While Judy perceives that her son interacting with other children would contribute to changes in his self-confidence, “I think he will come home, feel more liberated. Liberated the fact that he will meet	

Theme: Keeping It Going			
	(1) watching DVDs produced by past patients, and then (2) viewing a video of their own treatment under light sedation, resulted directly in their child becoming cooperative and compliant with treatment requirements while awake. (Shrimpton et al., 2013) that all participants continued to practice some form of MBSR following program completion... (Sibinga et al., 2011) These children incorporated practical strategies from their peers and mentors into their day-to-day coping. (Stewart et al., 2013a) As well, their children were no longer using their heart disease as an excuse to not participate in activities. (White, 2014) The sustained changes in anxiety behavior demonstrated by Amber during a subsequent hospitalization also offered a correlation to previous research. Thompson and 73 Spacapan (1991), examined perceptions of control on vulnerable populations. The authors identified positive outcomes associated with the effects of a sense of control, and presented themes for further development. They also revealed a particularly useful application of perception of LOC which parallels the	and make new friends and he won’t feel alone – I think he will feel more assured of himself.” (White, 2014)	

Theme: Keeping It Going		
	data on Subject 2. The authors argued that ameliorative effects of control are residual, extending beyond the immediate situation over which an individual perceives control. (Wolf-Bordonaro, 2003)	

Theme: Keeping It Going				
Adoption into daily life/practise	None of the families engaged in the homework tasks that were provided, yet all felt that the handouts and articles were useful to keep as a reference. (Gan et al., 2010) Many parents continued to use the positive affirmation exercises upon completion of the study (Jaser et al., 2014) At the end of it she gave us this program handouts) so we can keep on going...I think I'll do really well with then. We got the BOSU and ... a packet of exercises to take home)....For the third group, the exercise physiologist began illustrating the utility of each exercise through pictures demonstrating how each exercise relates to daily physical tasks and including explicit guidelines for gradually increasing moderate-vigorous physical activity at home (ie, brisk walking, playing a sport, swimming) to emphasize the importance of increased physical activity outside of session....Least favorite the long muscle relaxation. It just took too long. Less preferred coping skills were those that required more time to complete or those that they practiced less frequently (e.g., progressive muscle relaxation)...Least favorite the long muscle relaxation. It just took too	‘‘It’s been going good. Usually do it in my room. I do it whenever I am wheezing.’’... ‘CD, it was more easier to do than reading it’’ ... ‘Nothing has gotten in the way, I just remember, no one reminds me’’ ~ ‘‘Busy household’’ [got in the way of practicing] ~ ‘‘It’s better doing the techniques at school, it is so loud at my house’’ (Bignall et al., 2015) “R: What did you not like about the program? P: R: Yeah. Anything else? P: It could have been longer. Not like each night, but longer in weeks. It would have been better if I had had my family there, like if I was close enough to my family to bring them.” (Brodeur, 2005) Another parent noted, “(My daughter) is very easily with Cellie. For example, in study 1 (Cellie Kit comments), one child stated, “I would use him wherever I go. I would bring Cellie with me to the hospital… he (would be) my buddy… and help me out.” Another child commented, “I like how you guys (had) the idea to make this for kids with cancer.” (Marsac et al., 2012)	Bignall et al., 2015, Brodeur, 2005, Gan et al., 2010, Jaser et al., 2014, Kashikar-Zuck et al., 2016, Marsac et al., 2012, Reme et al., 2013, Whittemore et al. 2010	Reminders: Engagement

Theme: Keeping It Going		
	long. Less preferred coping skills were those that required more time to complete or those that they practiced less frequently (e.g., progressive muscle relaxation)....Also, the integration of CBT with exercise requires in vivo exposure for maximal effectiveness. (Kashikar-Zuck et al., 2016) In study 1 (Cellie Kit comments), children reported that they would use the Cellie Kit for emotional expression, to practice techniques for talking to others about cancer, as a toy for fun, for comfort, and for distraction during procedures. (Marsac et al., 2012) In contrast, one of the participants valued the practical part higher than the education part, as expressed here: 'The practice, sort of practically standing up and walking through the process was the helpful bit... and the practical assignments as important for the rapid recovery....They had the opportunity to practise the process and apply it in their everyday life (Reme et al., 2013) Parents highlighted the need for visual examples, sequencing, and the opportunity to practice. (Whittemore et al. 2010)	

Theme: Keeping It Going			
Role of technology in continuing relationships	The relationships did not end with camp, Aside from the contacts provided during the camp reunion, clinic visits, and hospitalization, 27 children (54 percent) also stayed in touch through letters and telephone calls,(Bluebond-Langer et al., 1991) Nine participants revealed that campers developed enduring social networks and continued contact by a variety of means including visiting each other's home, making phone calls, texting, using electronic platforms, or meeting at the annual camp reunion.(Desai et al., 2014) Campers also maintained connections with other campers outside of camp through text messaging, email, and other electronic means.(Gillard et al., 2011) another which in some cases had led to 'offline' relationships through face-to-face meetings or interaction via social networking sites, email and text messaging. (Kirk et al., 2016) Girl 4: No, I haven't actually. We've been like, we've messaged a couple of times on Facebook and stuff but we haven't really actually seen each other. (New ChIPS Members Focus Group) (Lewis et al., 2016) and remaining connected to camp friends through time by using novel	Twenty-three children identified the importance of friendship as being special about their camp experience. Although many of the children only saw each other once a year at the camp, they describe stronger relationships with those peers than peers they saw on a more frequent basis. "She was the one I called when I got cancer. I don't know. Even though like we never see each other, I feel like she is one of my closest friends. Like, closer than the ones I have at school."(Bultas et al., 2015)	Bluebond-Langer et al., 1991, Bultas et al., 2015, Desai et al., 2014, Gillard et al., 2011, Kirk et al., 2016, Lewis et al., 2016, Moola et al., 2015, Stewart et al., 2011b, Tiemans et al., 2007, White, 2014

Theme: Keeping It Going		
	online technologies.... Social media was used as a way to manage the short-term nature of camp and to ensure that the children maintain their bonds through time.(Moola et al., 2015) Eight reported ongoing electronic contact with group members following completion of chat sessions. (Stewart et al., 2011b) As an example, a parent reported that her daughter received phone calls and e-mails from fellow campers after the camp to inquire about her surgery. Other parents reported ongoing peer socialization among campers via e-mail and social networking among teens. (Tiemans et al., 2007) Another way in which families were able to interact was through the social media website Facebook. Camp Oki has a camp specific Facebook page that is used as a platform for caregivers and campers to share experiences, comment on photos, and stay updated with camp related activities.(White, 2014)	

	Theme: Keeping It Going		
Interventionists role in maintaining connectedness	Nine participants revealed that campers developed enduring social networks and continued contact by a variety of means including visiting each other’s home, making phone calls, texting, using electronic platforms, or meeting at the annual camp reunion. (Desai et al., 2014) To ensure equitable access to social networks after camp, camp administrators could provide formal and informal opportunities for further relationship building and nurturing for campers. Doing so would provide further contact between the positive social context of camp and individuals, as well as provide opportunities to teach others about HIV/AIDS through advocacy and educational efforts. This would also influence the development of a sense of belonging to a larger, supportive community. (Gillard et al., 2011)		Desai et al., 2014, Gillard et al., 2011

Theme: Keeping It Going			
Top up or "refresher" sessions	Children and parents wanted relevant information from the point of diagnosis and onwards throughout the course of the disease (Barlow et al., 1999) others commented that it was good to have the review, despite being several years-post-injury (Gan et al., 2010) As mentioned earlier, learning music may combat late effects of cancer treatment. Six-year-old Camilla enjoyed participating in music therapy during radiotherapy for a brain tumor. Eighteen months after completing treatment, Camilla’s parents noticed that she had impaired memory, concentration, and attention difficulties. However, she was motivated during piano lessons and appeared to encounter fewer problems with her music learning and playing. Camilla was subsequently enrolled in additional instrumental lessons on the flute to support her learning and to hopefully reduce the cognitive long-term effects of her disease and cancer treatment. (O’Callaghan et al., 2013) Others described the whole treatment to be too short, with too little follow-up support afterwards. (Reme et al., 2013)		Barlow et al., 1999, Gan et al., 2010, O’Callaghan et al., 2013, Reme et al., 2013

Theme: Keeping It Going			
Anticipation/reminder/ transitional object	Remarkably, anticipating the novel theme for each year's camp along with the souvenirs and activities associated with it, in an otherwise familiar camp routine was also highlighted as meaningful. (Desai et al., 2014) Additionally, interviews with former campers at Teen Forum indicated that medication adherence learned at camp changed campers' clinical relationships with their doctors. At home, doctors were able to reference information learned at camp to reinforce adherence. An 18-year-old former camper shared her reasons for adhering to her medication regimen... Most campers discussed in detail how they reflected on and looked forward to opportunities for reprieve and recreation all year. One camper told another camper, "This is the most fun I have all year." The activities of anticipation and reflection were supported through camp mementos such as a memory book, diplomas, certificates, awards, and gifts from counselors.(Gillard et al., 2011) At camp, it was evident that participants (campers and counselors) felt connected to a phenomenon with a past and a future. For example, a camp volunteer created a DVD film of the previous year that camp	"it feels good...it can show happiness;" and child (002) "when I'm feeling sad they make me happy;" and child (004) "makes me happy, brings a smile...."it feels different , knowing that I have something to remember;" child (004) "looking back and already seeing how much I've gone through;" child (005) the BOC Program "makes me remember;"." (Baruch, 2012) "I'll tell you that it's something we won't forget. It will be a memory that we will share. Together, the four of us. And you know, we talk about things that we did at Living Well, you know, it's just.. .like the rocks. We refer to those rocks every now and then that we made. You know, "He's the smart rock, yeah and she's the pretty rock", you know things like that. Yeah, it's a memory that we will share." (Brodeur, 2005), "The meaning of camp in my life is everything. It's what I want to do every single summer. I look forward to it every single summer … So it's really, really fun." (Gillard et al., 2016) "I would use him wherever I go. I would bring Cellie with me to the hospital… he (would be)	Baruch, 2012, Brodeur, 2005, Desai et al., 2014, Gillard et al., 2016/13/11, Marsac et al., 2012, O'Callaghan et al., 2013, White, 2014/16

Theme: Keeping It Going			
	administrators and volunteers gave to potential and past participants, and showed on the first night of camp. During the showing, people reflected on past summer experiences, and adult staff whispered to each other about ways to further improve the camp experience based on specific activities shown in the film that could have been better implemented. Importantly, there was no sense that staff compared previous summers as either inferior or superior to the present summer. Camp staff made several efforts to create films, songs, and other artifacts to be seen in the future, such as cabin videos and crafts. Another example of maintaining connections in the camp community was observed during staff training when people cheered with increasing volume for those who shared the number of years that they had been involved in camp; while everyone was cheered, the loudest cheering occurred for those with 20–25 years of experience. For youth with cancer, hearing others' longevity and future-orientations suggested that they too could persevere and live a healthy life. (Gillard et al., 2013) In discussing enjoyment, many camper study participants talked about camp being the central focus of	my buddy… and help me out."... for talking to others about cancer, as a toy for fun, for comfort, and for distraction during procedures. One child commented, “If I'm scared (I could) hug it and talk to it.” Another noted, “(I would) squeeze (Cellie) when I'm getting poked.” (Marsac et al., 2012)	

	Theme: Keeping It Going	
	their entire year. Some claimed that they looked forward to camp more than anything else. In describing the meaning of camp, one camper stated (Gillard et al., 2016) Music is like a security blanket or transitional space...Lyrics are only one part of a song’s meaning: it is also derived from melody, harmony, rhythm (Levitin, 2008), and associated “feeling memories.” Songs can feel personal, special, and supportive because we “fill in” their meaning—they are “imaginatively interpreted” (Levitin, 2008). (O’Callaghan et al., 2013) Additionally, three caregivers used their children’s camp experience as a resource to reinforce good behaviours through mastery experiences. This allowed participants to connect back to what their children were able to accomplish at camp: I’m encouraging her now, ‘Amanda you went to camp, you did this at camp you can totally do this’. And that’s helped too, having the camp experience has really helped with whenever she does feel like she can’t do something I’m like, ‘well Amanda look at all the stuff you did at camp’, she’s like ‘oh you know what, right, I did do a lot of cool stuff’. And then she’s not really afraid to try new	

	Theme: Keeping It Going
	things now’. (Julie) (White, 2014) Not only was camp used to strengthen new behaviours but participants also used it as a tool to help reinforce within themselves that their children were able to function and be independent from their family. (White et al., 2016)

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Table 8: Components of interventions which may empower children and young people

Useful component (Third-order construct data)	Relevant themes	Articles contributing to construct
Increasing CYPs perceived control over environment to reduce potential distress	Empowerment	(Burns et al., 2010; Shrimpton et al., 2013; Wolf Bordonaro, 2005)
Encouraging CYP to identify what they would like outcome of intervention to be/goal setting	Empowerment	(Gan et al., 2010; Reme et al., 2013; Serlachius et al., 2012)
Sharing control with the intervention deliverers /Having an equal say	Empowerment, Mutuality Self-esteem	(Ayers et al., 2011; Barlow et al., 1999; Barnetz & Feigin, 2012; Campbell et al., 2010; Dennison et al., 2010; Gan et al., 2010; Ann Gillard & Watts, 2013; Kashikar-Zuck et al., 2016; Reme et al., 2013; Stewart et al., 2013b; L. White, 2014; Wolf Bordonaro, 2005) (Wright et al., 2004)
CYP choosing to what extent they engage with an intervention	Empowerment	(Barnetz & Feigin, 2012; Bluebond-Langer et al., 1991; Docherty et al., 2013; Gan et al., 2010; Ann Gillard & Watts, 2013; Kashikar-Zuck et al., 2016; Shrimpton et al., 2013; Stewart et al., 2013b)
Feeling able to ask for help	Empowerment, Social support	(Nicholas et al., 2007; Reme et al., 2013; Stewart, Barnfather, et al., 2011; Stewart et al., 2013b; L. White, 2014; Wolf Bordonaro, 2005)

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