

Supplementary Materials

Table S1. Promotors and inhibitors of hope generated by patients and caregivers.

STRUCTURAL LEVEL Domain	Promotors	Inhibitors
Healthcare research	<ul style="list-style-type: none"> • Access to research, knowledge/awareness of research for improving healthcare • Knowledge/awareness/pursuit of research going on to improve the healthcare system • Access to clinical trials • Research related to illness 	
Healthcare finance	<ul style="list-style-type: none"> • Access to all medications and services, regardless of insurance • Medical care for all; no insurance issues 	<ul style="list-style-type: none"> • Financial barriers; financial burden of ongoing medical bills*
Healthcare delivery	<ul style="list-style-type: none"> • Confidence in medical team that supports us* • More integrated, holistic, alternative medical approaches* • More mental health and emotional support* • Better transition from child to adult care* • Second opinions or options beyond medical care • Transition care • More support/follow up at home • Easier access/connection with providers (accessibility) support • Trust based patient/doctor relationship • More meaningful communication between medical teams • Access to social workers • Simplified questionnaires/assessments • More patient involvement in care • more involvement from patient with doctors/parents • Joy within the clinical setting (therapy animals, role model visits) • navigating healthcare system/patient navigator • better laws/policies to support communication between patients and doctors 	<ul style="list-style-type: none"> • Not being heard by providers; lack of faith, empathy, sensitivity, compassion, and attitude from doctors; being dismissed (provider)* • Difficulty managing logistics (insurance, appointments, prescriptions) • Feeling your care is lacking, not giving you everything you need (e.g., Struggling to get a port) • When others don't listen to you/your needs (provider) • Words people use (provider) • Lack of sensitivity, compassion, mindfulness, around privacy (provider) • Lack of communication between providers • negative/neutral delivery of news from doctors (provider) • Delays in diagnosis • Broken health system • Language and cultural barriers for access to service
INTERPERSONAL LEVEL		
Community & human connection	<ul style="list-style-type: none"> • Being a person outside the disease* • Community service (giving back) • Community/human connection outside illness community • Community/connection inside chronic illness community • Get support from others (peer support) • Sharing stories, hearing positive patient stories • Connecting with friends (in/out of hospital) • Helping family around the house • Getting involved (advocacy) • Getting involved in politics • Enjoyable activities (retail therapy, being outdoors, games, food/wine tours, pets, nails/hair done) • Camps related to illness • Mentorship programs; having a mentor • Positive patient stories • Hope role models • Family based activities 	<ul style="list-style-type: none"> • Not having connection to advocates • Isolation • Lack of socialization • Stigmatization
Practical support	<ul style="list-style-type: none"> • Having resources that give us more time to do 'stress-relieving' activities 	

	<ul style="list-style-type: none"> • Get help with logistics of care to allow time for enjoyable activities • Respite services (e.g., various home help- errands, cleaning etc.) • Help from schools (support services) 	
INTRAPERSONAL LEVEL		
Spirituality	<ul style="list-style-type: none"> • Spirituality and access to spirituality-based resources • Faith/ Daily prayers 	
Self-development & Knowledge	<ul style="list-style-type: none"> • Taking a leadership or mentoring role yourself • Identifying goals and specific aspirations • Aspirations for the future • Get more information (consult resources) • Knowledge • Self-care • Unburying interests • Art, music & other creative activities • Traveling • Planning for the future (e.g., job, travel) 	<ul style="list-style-type: none"> • Lack of access to information or knowledge
Psychologic wellness & emotional work	<ul style="list-style-type: none"> • Acceptance • Acceptance of new normal • Validation/acknowledgement of feelings and situation • Willingness to be vulnerable • Getting support from a professional (e.g., therapist, SW, etc.) • Having a routine • Staying in the present moment/day • Bringing things to look forward to into hospital setting • Something to look forward to • Not aiming for perfection (e.g., accepting child as they are) 	<ul style="list-style-type: none"> • Uncertainty about the future* • Feeling alone, fear, sadness, depression, and stress*
Physical wellness	<ul style="list-style-type: none"> • Stress relievers (e.g., movement, anything that gets me in motion) 	<ul style="list-style-type: none"> • Health setbacks • Harmful impacts of medications • Pain and other physical impacts

Items are separated according to level of influence (structural, interpersonal, intrapersonal) and domain. * indicated promoters and inhibitors that were rated highly (≥ 6 votes) for importance by patients and caregivers .