

Table S3: Codes, factors and group of factors associated with experience of hope

Codes Associated with Increased Experience of Hope
Acceptance of illness
Access to comfort care and chemotherapy
Access to innovative therapies
Access to medical care
Access to new treatments
Access to regular transfusions
Access to relevant information
Access to respite care
Acknowledgment and acceptance of uncertainty
Acknowledgment by physicians
Acknowledgment of hopes beyond cure
Acknowledgment of the child as a person
Active caregiving
Active role in treatment decisions

Codes Associated with Decreased Experience of Hope
Absence of clear health support structure
Absence of cultural/language alignment
Absence of early goals-of-care planning
Absence of information
Absence of in-person connection
Absence of other children in household
Absence of partner
Absence of recognition
Absence of shared understanding
Absence of structured psychosocial intervention (usual care only)
Accurate understanding of poor prognosis
Ambiguity about disease progression
Ambiguity in prognosis
Ambivalence about treatment

Activities and entertainment
Affect-oriented responses
Affirmation from therapist
Affirmation of parental abilities
Agreement with child's living will
Alleviation of suffering
Altruistic motivation
Autonomy
Avoiding emotionally draining conversations
Avoiding negative information
Balanced information
Being given realistic hope
Being included in care
Being informed
Belief in future treatments
Belief in God
Belief in god's plan

Anticipated severe disability
Anticipatory grief
Anxiety about child's future
Anxiety about losing the child
App technical issues, limited language accessibility of app
Avoidance of difficult topics
Avoidance of end-of-life conversations
Awareness of limited treatment efficacy
Awareness of mortality
Awareness of physical decline
Behavioral disengagement
Bureaucratic uncertainty
Caregiver exhaustion
Certainty of incurability
Clear signs of deterioration
Clinical deterioration
Clinician avoidance

Belief in helping future patients
Belief in high chance of cure
Belief in treatment efficacy
Belief in treatment improvements
Benefit finding
Better emotional adjustment
Better medical knowledge
Caregiving role prioritized
Celebrating joy
Celebrating milestones
Celebrating milestones
Child as coping source
Child's vitality
Child's well-being
Church attendance
Clarity
Clear communication

Cognition-oriented responses without emotional support
Cold or routine communication by staff
Communication difficulties
Conflicting feelings between acceptance and denial
Conflicting information
Conflicting medical advice
Conflicting medical opinions
Conflicting messages from care team
Conflicting treatment suggestions
Cultural resistance to palliative care
Decisional doubt
Child expressing desire to die
Child's deteriorating condition
Child's deteriorating health
Child's medical complications
Child's suffering
Child's visible suffering

Clear goals
Clinical improvement of child
Clinician presence
Cognitive flexibility
Cognitive reframing
Communication with healthcare professionals
Community connection
Confidence in medical team
Connecting with others
Continuing bond
Continuing daily routines
Control over symptoms
Convenience of online writing
Coordinated perinatal care
Courageous coping
Cultural/language matching

Decline in domains like pain and suffering
Defensive coping
Delayed or unclear communication about prognosis and PC/EOL
Delayed treatment
Depressive symptoms
Diagnosis of leukemia
Difficulty in planning ways to reach goals
Direct and hopeless communication from medical staff
Disagreement with establishing a living will
Disappointing or no treatment recommendations
Discouraging questions from the surrounding community and medical staff
Disease progression
Disease recurrence
Disempowering environments
Disfigurement
Disrupted faith practices

Daily meaningful moments
Day-to-day focus
Demonstrating intent to cure
Desire to return home
Determination
Development of new domains over time
Discussion of end-of-life care
Early prognosis discussion
Early, empathic, honest goals-of-care discussions using complete intervention
Education and training by nurses
Emotional closeness
Emotional decompression
Emotional support
Emotional support from caregivers
Empathetic and respectful HCP approach
Empathetic communication by healthcare staff

Distrust in local care
Emotional and physical exhaustion
Emotional burden of caregiving
Emotional burden without spiritual support
Emotional disengagement
Emotional dissonance
Emotional distress
Emotional exhaustion
Emotional isolation
Emotional isolation or judgment
Emotional turmoil
Emotionally taxing conversations
Ethical concerns about hope sharing
Excessive optimism
Exclusion from care
Exclusion from communication

Empathetic providers
Empathy from hcps
Empowerment
Engaging in enjoyable activities
Expectation of more treatment options
Faith
Faith in divine intervention
Faith in medicine
Faith/spirituality
Family activities
Family and social support
Family and social support
Family communication
Family rituals
Family togetherness
Family/community support
Feeling heard

Exclusion from decisions
Exclusion from information
Exclusion of child
Exhaustion
Exposure to negative prognoses
False expectations
False reassurance
Fear
Fear of death
Fear of disappointment
Fear of exclusion from treatment
Fear of future complications
Fear of premature death
Fear of relapse
Feeling ignored by medical staff and family
Feeling of abandonment
Feeling of giving up

Feeling heard and valued
Feeling supported
Feeling supported by professionals
Flexibility in care
Flexible format of care
Focus on family time
Focusing on present
Frequent online consultation
Future-oriented goals
Gaining experience
Goal reappraisal
Goal setting
Good communication with medical staff
Gradual planning
Gratitude
Guidance

Feelings of guilt and failure
Financial burden
Financial concerns
Financial difficulties
Financial strain
Focus on immediate survival
Frequent hospitalisations
Guilt
Guilt and regret
HCP discomfort
Healthcare fragmentation
Helplessness
High mortality prognosis
High perceived uncertainty
High stress
High vicarious despair
Higher baseline psychological distress

Having dreams for the future
Having no financial concerns
Healthcare provider support
High vicarious hope
Higher baseline hope
Higher education
Higher family functioning
Higher positive affect
Highlighting positives
High-quality communication style
High-quality prognostic information
Honest and frequent communication
Honest but hopeful communication
Honest yet compassionate communication
Honesty from clinicians (in this case oncologists)
Hope for cure or stabilization
Hope for child's well-being (cure, love, quality of life)

Higher levels of illness-related uncertainty
Higher negative affect
Higher perceived uncertainty
Illness-related distress
Inability to make time for oneself
Inability to process emotions
Inadequate communication
Inadequate hospital facilities
Inadequate information
Inadequate psychosocial support
Inadequate symptom management
Inappropriate communication from healthcare providers
Information concealment
Information overload
Initial diagnosis
Initial diagnosis shock
Initial fear of giving up curative treatment

Hope for improvement
Improvements in child's condition
Improvements in physical condition
Improving condition
Inclusion in care decisions
Inclusion in clinical discussions
Inclusion in discussions
Inclusion of child in discussion
Information from medical staff and peers
Information seeking
Informative caregiving education
Involvement in care
Involvement in decisions
Involvement in planning
Involving child in decisions
Journaling
Joyful clinical environment

Insensitive communication
Insensitive prognoses
Interference of illness with daily activities
Internal ambivalence
Internalized emotional suppression
Intractable symptoms
Invasive treatments
Isolation
Judgmental attitudes
Lack of access to treatment
Lack of alignment in values and communication
Lack of anticipatory guidance
Lack of clear information
Lack of communication
Lack of community support
Lack of consensus between parents
Lack of continuity

Kindness of medical staff
Lasting relationships
Leaning into faith
Learning from others' grief journeys
Less traffic pressure
Letting go
Logistic and financial aid
Lower baseline distress
Lower illness-related uncertainty
Maintaining daily life and presence of child
Maintaining future plans
Maintaining honesty
Maintaining identity beyond illness
Maintaining peaceful relationships
Meaningful milestones (e.g., college plans)
Meaningful reflection

Lack of control
Lack of coordination
Lack of deeper discussion on key topics
Lack of direct discussion about hope by clinicians
Lack of discussion about end-of-life care
Lack of emotional support
Lack of empathic communication
Lack of empathy from providers
Lack of energy
Lack of individualized communication
Lack of information
Lack of information on start/enrollment of specific modality of care
Lack of interaction during consultations
Lack of medical resources
Lack of parental skills to communicate
Lack of peer contact

Meaningful rituals
Meaningful time with child
Meaning-making
Memory-making
Messages from deities
Mindfulness
Moments for self-care
Naming rituals
Nonabandonment messages
Normalization
Oncologists' clear explanation of cure
Ongoing evaluation of child's condition
Online and interpersonal information seeking
Online support groups
Open and honest communication
Open clinician communication
Open communication

Lack of peer interaction
Lack of plan implementation
Lack of professional guidance
Lack of prognosis
Lack of religious framework
Lack of social support
Lack of societal understanding
Lack of support
Lack of support from oncologist
Lack of support networks
Lack of time for self
Lack of trust
Lack of understanding
Limited access to medical services
Limited communication
Limited opportunity to say goodbye
Limited prognostic clarity

Open communication with care team
Open discussions about death
Opportunity to say goodbye
Optimistic expectations
Optimistic family members
Optimistic future orientation
Optimistic thinking
Organized activities for children
Parental adaptation
Parental agency
Parental and sibling support
Parental belief in doing their best
Parental emotional support
Parental participation in care
Parental peer support
Participation in normal activities
Participation in research

Limited session duration
Long wait for results
Loss of communication
Loss of control
Low education
Low income
Low spiritual reliance
Low spirituality
Lower ability to find benefits in stressors
Lower confidence in coping
Medical pessimism
Medical pressure to terminate
Medical uncertainty
Minimal impact of faith or prayer
Minimal space for parental expression
Misinformation
Mixed treatment results

Participation in trials
Peer connection
Peer reassurance
Peer support
Peer support from others with similar experience
Perceived contact with the child
Perceived child responsiveness
Perceived physical improvement
Perceived physician confidence
Perceived potential for prolonged survival and improved QoL
Perceived social support
Perceived support from clinicians
Perception of control
Perception of hospital as a safe space
Personal coping strategies like blogging
Physical therapy
Planning for quality time

Negative comparisons
Negative illness effects
Negative past experiences
Negative provider attitudes towards religion
Negativity from others
Neglect of other children
Ongoing despair
Open discussions about prognosis
Organ rejection
Overly blunt or false reassurances
Overly clinical or blunt information delivery
Overwhelm
Overwhelming caregiving burden
Overwhelming caregiving demands
Overwhelming information
Overwhelming obstacles
Overwhelming or premature planning

Planning ways to reach goals
Playful information methods
Positive attitude
Positive clinician attitude
Positive communication
Positive framing of bad news
Positive illusions
Positive information
Positive narratives
Positive outcomes of curative treatment
Positive parental attitude
Positive reframing
Positive relationships
Positive thinking
Positive treatment outcomes
Positive treatment response
Possibility of future

Pain
Paralyzing uncertainty
Parental burnout
Passivity
Perceived abandonment by god
Perceived discrimination
Perceived futility
Perceived hopelessness
Perceived hopelessness by providers
Perceived invisibility
Perceived suffering
Perceived suffering of child
Perception of illness as external destructive force
Perception of staff resignation
Perception of steep health decline
Perception of suffering
Persistent uncertainty

Postnatal diagnosis
Prayer
Prayers
Preparing for end of life
Presence in daily life
Presence with child
Present-focused coping
Pride in child's strength
Proactive planning for care
Professional care
Professional support
Protective communication
Proximity to family
Psychoeducation
Psychologists' use of metaphors and drawings
Quality of life
Quality time

Pessimistic reactions
Physical and emotional exhaustion
Physical differences
Physical limitations
Physicians' avoidance of discussions
Poor communication
Poor communication timing
Poor communication with palliative team
Poor hospital communication
Poor prognosis understanding
Poor timing of discussions
Pre-existing fatalistic beliefs
Prenatal diagnosis
Preoccupation with diagnosis
Pressure to decide quickly
Pressure to make end-of-life decisions
Pressure to terminate pregnancy

Reassurance
Redirecting to broader hopes
Re-engagement with daily life
Reframing by professionals
Reframing narratives
Reframing normality
Relational support
Relationship building
Religious belief
Religious faith
Religious/spiritual beliefs
Remission
Repeated clear communication
Resilience training
Resiliency
Resolution of diagnosis
Resources

Prior community experiences with death
Professional communication about end-of-life
Prognostic uncertainty
Progression of symptoms
Progressive disease
Prolonged dying
Questioning the future
Realistic or pessimistic prognostic communication
Reduced goal-directed thinking
Reduced quality of life as death approaches
Routine/unempathetic hcp behavior
Sad memories evoked during interviews
Self-blame
Self-isolation
Separation from home and daily life
Short duration of care
Social isolation

Respect for family values
Respectful and personalized care
Restructuring social interactions
Returning home
Safe space to share
Securing accurate diagnosis and good treatment
Seeing child healthy
Selective sharing of updates
Self-efficacy
Self-reflection
Sense of agency and pathways to goals
Sense of agency in decision-making
Sense of normality
Sense of purpose
Shared experiences with other ds families
Shared understanding with clinicians
Sharing success stories

Social stigma
Social stigma or ridicule when expressing spiritual experiences
Societal misunderstanding
Socioeconomic challenges
Spiritual depletion
Spiritual doubts
Stigma and spiritual interpretations (e.g. Curses)
Stigmatizing language
Symptom burden
Systemic barriers
Systemic disorganization
Teasing by peers
Treatment failure
Treatment side effects affecting appearance
Uncertainty
Uncertainty about future care
Uncertainty about long-term treatment effects

Signs of clinical improvement
Signs of infant improvement
Sincerity of professionals
Social support
Spiritual and social support
Spiritual belief
Spiritual connection
Spiritual growth
Spiritual meaning
Spiritual meaning-making
Spiritual or medical trust
Spiritual perspective
Spiritual practices
Spiritual reflection
Spiritual support
Spirituality
Stable occupation

Uncertainty in diagnosis
Uncertainty of prognosis
Unclear caregiver roles
Unclear or overly simplified language
Unclear questions
Underestimation of long-term limitations
Unfulfilled expectations
Unmanaged symptoms
Unmet basic needs
Unmet expectations from providers
Unmet sibling support needs
Unresolved status
Unsupportive social environment
Unsupportive social interactions
Use of dehumanizing language
Vague communication
Value-laden language

Staying at home with child
Structured study design
Successful curative treatment outcomes (in this case surgical)
Successful treatment (in this case transplant) outcomes in other children
Sufficient income
Support (emotional, spiritual, financial)
Support for decision-making
Support for individual goals (e.g., normalcy, friendships)
Support from associations
Support from clinicians
Support from emotionally affirming individuals
Support from family
Support from friends/faith communities
Support from medical staff
Support from others
Support from peer groups and healthcare providers

Visible relapses
Waiting endlessly
Witnessing child's suffering
Working outside the home
Worsening illness

Support from relatable peers
Support from religious groups
Support groups
Support in religious practices
Supporting child autonomy
Supportive clinician relationships
Supportive communication
Supportive environment
Supportive family
Supportive healthcare relationships
Supportive hospital staff
Supportive maternal identity
Supportive perception of care
Supportive psychosocial environment
Supportive relationships
Survival beyond expectations
Symbolic signs (butterflies, music, light)

Symptom control
Symptom management
Tailored information sharing
Team alignment
Therapeutic letters
Timely and respectful conversations
Timely communication
Transparency in treatment process
Trust in providers
Trusting relationships with providers
Truthful but sensitive communication
Visible improvement in condition
Written plans reflecting family values

Factors and Groups of Factors Associated with Increased Experience of Hope	
Groups	Factors

Factors and Groups of Factors Associated with Increased Experience of Hope	
Groups	Factors

Open Communication and Information Sharing	Clear and honest communication
	Early information
	Prognostic discussions
	Questions are being answered openly

Information Gaps and Conflicting Messages	Lack of information
	Unclear explanations, conflicting messages
	Technical language

Trusting Relationships with Healthcare Providers	Caring, present, and supportive team
	Not being alone
	Listen, “take their time,” and show compassion

Social Isolation	Social Isolation
	Lack of support network
	Being excluded from family conversations
	Being excluded from hospital visits

Family and Social Support & Togetherness	“Companionship” with loved ones
	Possibility of staying at home with the child
	Presence of other family members

Child’s Deteriorating Condition and Suffering	Visible suffering
	Worsening symptoms
	Health crises
	New complication
	Illness relapse
	Frequent hospitalizations

Spiritual and Religious Faith	Religious faith
	Praying
	Participating in religious ceremonies
	Receiving support from faith communities

Uncertainty and Loss of Control	Uncertainty related to the disease
	Perceived loss of control
	Bureaucratic or systemic uncertainty

Effective Symptom Management and Comfort	Effective symptom control
	Signs of clinical improvement

Emotional Distress and Mental Exhaustion	Overwhelming emotions such as fear, anxiety, depression, guilt, and grief
	Stress

Involvement, Control and Empowerment	Being treated as a valued member of the care team
	Active participation in the child's care and decision-making process

Caregiver overload	Financial problems
	Logistical burden of caring

Positive Outlook and Coping Strategies	Optimistic mindset
	Active coping
	Building self-efficacy and self-confidence

Negative Encounters with Healthcare System	Dehumanizing language
	Judgmental attitudes from healthcare staff
	Fragmentation or lack of continuity of care
	Bureaucracy and delays of care support

Meaning-Making and Legacy Activities	Finding meaning and purpose
	Creating positive memories
	Celebrating milestones
	Sense of legacy and continuity
	Fulfill a child's wishes
	Opportunities to say goodbye properly

Cultural and Spiritual Distress	Cultural conflicts in care
	Spiritual doubts
	Sense of punishment
	Crisis of faith
	Stigma from their community
	Cultural resistance to concepts like palliative care

Financial and Practical Stability	Financial security or assistance
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