

THE LANCET

Supplementary appendix

This appendix formed part of the original submission and has been peer reviewed.
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Supplement to: Dalton L, Rapa E, Ziebland S, et al. Communication with children and adolescents about the diagnosis of a life-threatening condition in their parent. *Lancet* 2019; **393**: 1164–76.

Appendix

Methods

1. Literature Review

A narrative approach was adopted to provide a comprehensive overview of the available literature and address the wide ranging research questions outlined above. This inclusive methodology was particularly important given the breadth of available literature, ranging from large scale randomised controlled trials (RCTs) to qualitative studies exploring the detail of patient experiences. The search strategy focused on publications since 2000. However, in the context of evolutionary changes in healthcare philosophy around communication, different rates of change across high income countries (HICs) and LMICs, and gaps in the recent literature, we also included consideration of earlier studies (See Search strategy and selection criteria box in main manuscript and table 1 below).

2. Expert Group Meeting and Development of Framework

In the context of the available research evidence and limited child-focused, evidence-based guidelines, an interdisciplinary expert group was convened to synthesise the theoretical, academic and clinical experience of the members to develop a framework for communication. The workshop was attended by 16 professionals and an additional 4 members contributed to subsequent discussions, review and framework development to create an expert group (n=20). The group members had experience of working in HICs (Denmark, Sweden, UK, USA) and LMICs (Cameroon, Laos, Mozambique, Myanmar, Pacific Countries of Vanuatu and Fiji, Pakistan, Rwanda, Sierra Leone, South Africa, Tajikistan, Tanzania, Timor-Leste, Uganda) with backgrounds in psychology, psychiatry, paediatrics, oncology, palliative care, global health, child development, child protection, health and human rights, education, anthropology and sociology. The workshops included presentations on the literature review in HICs and LMICs and the academic and clinical work of the assembled group. Although caregivers and children were not direct participants of this workshop, a series of videos presenting parents' perspectives about talking to children about life-threatening conditions were reviewed (these have been published as a clinical and training resource at <http://healthtalk.org/content/talking-children-about-parents-life-threatening-illness>). Following extensive discussion, core principles were derived for use in developing a framework. This was then further refined through consensus to create a basic framework. During this iterative process, information gaps were identified and future research directions discussed. The framework was also reviewed by a parent currently undergoing treatment for cancer. We use the term parent throughout, but note that in some circumstances it may be a caregiver rather than a parent.

Table 1: Search strategy used in Medline (OvidSP)[from 1946]. Other strategies are available on request.

# ▲	Searches	Results
1	(child* or schoolchild* or pediatric* or paediatric* or boys or girls or adolescen* or teen* or youth? or young people or young person?).ti.	882902
2	communication/ or information seeking behavior/	69970
3	(nurse-patient relations/ or physician-patient relations/) and (communicat* or talk* or discuss* or disclose? or disclosure).mp.	29711
4	(parent-child relations/ or father-child relations/ or mother-child relations/) and (communicat* or talk* or discuss* or disclose? or disclosure).mp.	9697

5	Truth Disclosure/	12260
6	(communicat* or talk* or discuss* or disclose? or disclosure).ti.	97059
7	((communicat* or talk* or tell* or told or discuss* or disclose? or disclosure) adj3 (truth or diagnos* or prognos* or death or dying or terminal*)).ti,ab.	20672
8	2 or 3 or 4 or 5 or 6 or 7	191951
9	1 and 8	14897
10	((communicat* or talk* or discuss* or disclose? or disclosure) adj3 (child* or schoolchild* or pediatric* or paediatric* or boys or girls or adolescen* or teen* or youth? or young people or young person?)).ti,ab.	12176
11	9 or 10	23230
12	Attitude to Death/	14364
13	exp Terminal Care/ or Terminally Ill/	46221
14	Palliative Care/	44439
15	exp Advance Directives/	6332
16	((lifethreaten* or life threaten* or terminal*) adj2 (ill* or condition?)).ti,ab.	13522
17	(advanced directive? or living will? or "do not resuscitate" or resuscitation order? or assisted suicide?).ti,ab.	5701
18	((place or home or hospice) adj2 (die or dying or death)).ti,ab.	2190
19	((palliative or hospice? or "end of life" or terminal) adj2 (care or therap* or treat*)).ti,ab.	36763
20	*neoplasms/ or exp *breast neoplasms/ or exp *colorectal neoplasms/ or exp *testicular neoplasms/	647765
21	exp *leukemia/ or exp *lymphoma/	275110
22	*Brain Neoplasms/	76640
23	(cancer* or carcinoma? or tumour? or tumor? or malignan* or metasta*).ti.	1562751
24	((breast or testic* or colon* or bowel or colorect* or colo-rect* or brain) adj3 (cancer* or carcinoma? or tumour? or tumor? or malignan* or metasta*)).ti,ab.	445150
25	(leukaemia or leukemia or lymphoma?).ti,ab.	330877
26	*hiv infections/di	7520
27	((hiv or human immunodeficiency virus?) adj3 (disclose? or disclosure or diagnos* or prognos*)).ti,ab.	11046
28	Hemorrhagic Fever, Ebola/	2784
29	ebola.ti,ab.	4794
30	12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29	2278846
31	11 and 30	1744
32	limit 31 to "reviews (maximizes specificity)"	23
33	(Qualitative systematic review* or (systematic review and qualitative)).ti,ab.	3131
34	(evidence synthesis or realist synthesis).ti,ab.	2023
35	(Qualitative and synthesis).ti,ab.	4232

36	(meta-synthesis* or meta synthesis* or metasyntesis).ti,ab.	559
37	(meta-ethnograph* or metaethnograph* or meta ethnograph*).ti,ab.	269
38	(meta-study or metastudy or meta study).ti,ab.	65
39	(realist review? or realist synthesis).ti,ab.	199
40	systematic review*.ti,ab. and qualitative research/	416
41	33 or 34 or 35 or 36 or 37 or 38 or 39 or 40	8731
42	31 and 41	4
43	32 or 42	24

Table 2: Studies concerning communication with children about life threatening illness in their parent

Author	Qualitative or Quantitative	Size of study (n)	Type of participants	Child age range in years (mean)	Parental diagnosis	Method of recruitment	Method & measures	How was communication assessed?	Results	Location
Armistead, Tannenbaum et al. 2001 ⁴⁸	Mixed methods	174	87 HIV-positive mothers ; 87 children	6-11	HIV	HIV clinic	Disclosure classed as: disclosed or non-disclosed (maternal rating). Semi structured interviews (child reaction to disclosure). Mothers: PSI, CBCL. Child: CBCL, CDI	Disclosure status	Less than 30% of mothers disclosed to their children. Disclosure more likely in families with lower incomes & mothers who reported being more bothered by physical symptoms. Higher rates of disclosure to girls & to older children. Disclosure unrelated to internalising or externalising problems	USA
Barnes, Kroll et al. 2000 ⁴⁶ , Barnes, Kroll et al. 2002 ⁵⁰	Mixed methods	88	32 mothers ; 56 children	5-18	Stage I or II breast cancer	Mother's medical team	Semi structured interviews (timing & extent of communication about diagnosis & treatment, reasons & barriers for communication) . Total communication scores	Content analysis & total communication scores	Mothers gave their children varying levels of information at different stages of the diagnostic/treatment journey; 70% given information after second outpatient visit when diagnosis confirmed by biopsy. Older children told earlier about parental illness. Children of more educated mothers given less information. Child gender did not effect total communication. Most common reason for not communicating was avoidance of children's questions, particularly about death. Many mothers wanted advice from HCP about how to talk to their children	UK

							calculated based on categorisation of interview responses		about illness	
Beale, Sivesind et al. 2004 ¹³	Qualitative	28	Children	3-18	Cancer (locally recurrent or metastatic)	Parents' medical team & palliative care service	Semi structured interviews or play based assessment for ages 3-8 (emotional response to parental cancer)	Content analysis	Children with dying parents had greater understanding of their parent's illness than their parents thought. Even small children were aware of parent's medical condition & implications	USA
Bugge, Helseth et al. 2009 ⁷⁷	Qualitative	13	6 patients ; 7 partners & ex partners	5-18	Incurable cancer (breast, bowel, brain, pancreas)	Part of The Family Support Program	In depth interviews (experiences of family illness and Family Support Program)	Kvale guidelines	Parents concerned about harming their children by not telling them in the 'right' way or at the 'right time'. Parents wanted guidance from, & a shared responsibility for their child's wellbeing, with HCP. Parents needed reassurance & validation about how they had communicated their illness with their children thus far. Separated parents found it helpful to have facilitated conversations in order to support their mutual children. Parents found it helpful to have information about children's normal reactions to such circumstances to understand their child's behaviour. Parents reported the programme helped their children talk more within the family about how they were coping & in voicing the 'difficult questions' which might otherwise be too difficult to raise	Norway
Bylund-Grenklo, Kreicbergs et al. 2015 ¹⁵	Quantitative	622	Bereaved child	18-26 (age 13-16 at time of bereavement)	Cancer	Population based survey	Swedish National Causes of Death Register & Multi-generational Register used to identify parents & children respectively. Postal questionnaire developed by study team (awareness of parental death & extent of communication with dying parent)	Questionnaire	98% reported teenage children should be informed when the parent's death was imminent, but only 59% had been informed. Often parent(s) and teenage children pretended that the illness was not that serious to avoid communication	Sweden
Christ and	Qualitative	87	Children	3-11	Cancer	Children of	Individual	Content	3-5 year olds observe physical manifestation	USA

Christ 2006 ²⁰	e					participants enrolled in a parent guidance intervention for families beginning 3-6 months pre bereavement & 14 months after parental death	interviews 6 months before death anticipated, at time of parent's death, and during immediate post-bereavement period. Interviews (experience of parental illness, death & bereavement)	analysis	of parent's illness but cannot understand permanence of death. Children need a concrete description of what death means & caregivers should anticipate children's questions will be frequent & repetitive. Authors recommend parents ensure that children are adequately supported when visiting sick parent; uncontained parental grief & distress can be frightening for children. 6-8 year olds need simple, concrete information & simple explanations about parent's behaviour, appearance, symptoms & treatment to avoid magical thinking. Children may have variable awareness of parent's imminent death & are sensitive to emotional state of parents & react accordingly. 9-11 year olds can use logical thinking to understand cause & effect, but still require concrete explanations & sequenced information	
Christ, Siegel et al. 1993 ¹⁸	Qualitative	87	Children	7-11	Advanced/terminal cancer with expected survival time of 6 months	Cancer Centre	Individual interviews (experience of parental illness & death) with children before parent had died	Content analysis	Common fears & concerns; impact of illness & side effects on children, fear of parent's death. Children's developmental understanding of illness & death can lead to misunderstandings of the cause of illness & visible symptoms in the absence of concrete information from parents	USA
Chowns 2013 ⁷⁴	Qualitative	9	Children	7-15	Cancer	Social worker in palliative care team	Participant researched their own lived experiences by making a group DVD	Content analysis	Adolescents' experience a sense of isolation, uncertainty about the future & need support in facing the anticipated difficulties ahead, rather than protection from them. They want the truth about their parent's condition & comprehensive, timely information	UK
Davey, Tubbs et al. 2011 ⁷⁶	Qualitative	12	Children	11-18	Breast cancer	Parents' medical team	Three focus groups with semi-structured discussion format (experience of parental diagnosis, treatment, relationship & emotional response)	Content analysis	Children found it hard to share feelings with friends who had not experienced parental cancer. Described feeling overlooked & unappreciated by their parent's medical team. Keenly aware of their parents' treatment regimen & side effects. Wanted a teen group around the time of diagnosis & treatment. Preference to talk to young people, but acknowledged some incentive might be necessary to encourage them to attend the group initially.	USA
De Baets, Sifovo et al. 2008 ⁶⁴	Quantitative	195	64 HCPs; 131 community	0-12	Community sample considering factors influencing	Primary healthcare centres (not specifically parents')	Disclosure classed as: Full disclosure (to have all information);	Descriptive analysis	For a hypothetical situation, 63% of participants expressed the need to give a child some information about the parent's HIV status, with 69% opting for full disclosure to children older than 11 years.	Zimbabwe

			members		HIV disclosure in hypothetical scenarios		Partial disclosure (being told there is a disease, but not specifically HIV); No disclosure (being told nothing) 32 item questionnaire (related to disclosure) developed by researchers plus 7 questions specific for HCP about their confidence in assisting with disclosure		HCPs opted for partial & full disclosure at significantly younger ages than community members. Higher levels of education associated with full disclosure at a significantly younger age. Up to a third would prefer to initiate conversations about HIV disclosure & grief with own children without assistance. However over half would prefer to have involvement from a health worker & 40-50% have help from a family member (most commonly father's sister & grandmother, rather than partner)	
Edwards, Watson et al. 2008 ²⁹	Quantitative	109	56 adolescents; 53 mothers	11-17	Stage I/II breast cancer	Single cancer centre	Adolescent: YSR of CBCL, CHQ-MH, C-IES, FAD, FES. Mothers: BDI, SF8 version of Medical Outcomes Health Survey	FAD	Poor family functioning & cohesiveness associated with adolescent emotional & behavioural problems. Poor family cohesiveness associated with increased stress responses. Internalising & externalising behaviour significantly associated with poor communication & poor affective responses	UK
Ellis, Dowrick et al. 2013 ¹⁶	Qualitative	33	Adults who had experienced the death of a parent before the age of 18	13m-17yrs at time of death 20-80 at time of study	Mixed group including cancer, heart attack, stroke & trauma	Community recruitment through media	Participant chose to write their experience or take part in an in depth narrative interviews (impact of parental death)	Narrative analysis	Distress compounded when children not given accurate information. Some described "implicit rules" for not speaking about the deceased parent had a negative impact on family functioning	UK
Ernst, Beierlein et al. 2013 ⁶⁶	Quantitative	1809	Adult patients diagnosed no more than 6 yrs	<22	Cancer	Cancer registries	HADS, OSSS, FAD, SF-8, Likert scales regarding use of psychosocial support	Not measured	73% of cancer patients with children wanted either information (about how to talk to their child about cancer, common emotional responses of children to such news) or active psychosocial support regarding issues pertaining to parental cancer. 9% of participants had accessed family or child-centred support; rates of satisfaction with this input were high.	German
Forrest, Plumb et al. 2006 ¹⁴	Qualitative	68	37 mothers; 31 children	6-18	New diagnosis of stage I-IIIa breast	Single cancer centre	Individual semi structured interviews (child awareness,	Thematic analysis	Even the youngest children were aware of cancer as a life threatening illness. Children suspected something was wrong before they were told the diagnosis. Parents sometimes	UK

					cancer		understanding, reaction to diagnosis & treatment, informational needs)		misunderstood their children's reactions & underestimated the emotional impact of the illness. Parents did not always recognise the child's need for preparation & age appropriate information about the illness, treatment & side effects	
Forrest, Plumb et al. 2009 ²²	Qualitative	57	26 non-affected fathers; 31 children	6-18	Maternal new diagnosis of stage I-IIIa breast cancer. Child interviews 3-6 months after diagnosis	Single cancer centre	Individual semi structured interviews (child awareness, understanding, reaction to diagnosis & treatment, informational needs). Child interviews sometimes included drawing & play	Thematic analysis	Fathers wanted to protect & reassure their children but felt this was hindered by insufficient information about breast cancer. Fathers did not always recognise the extent of their child's distress or misinterpreted signs of distress. Children were aware of their fathers' distress & wanted to protect him.	UK
Giesbers, de Leeuw et al. 2010 ⁵¹	Qualitative	137	129 children ; 8 adults	8-46 (15.3, median 14)	Cancer	Users of website for children of parents with cancer	Analysis of forum discussions on Dutch website (www.kankerspoken.nl) over a 3 month time period	Content analysis	Young people used website to share personal experiences, provide encouragement/support or seek information & advice. Children regularly faced emotional problems & experienced a lack of understanding & communication in their direct environment	Netherlands
Harris and Zakowski 2003 ²⁸	Quantitative	50	Adolescents	12-19 (15.7)	Cancer diagnosed within last 5 years	Cancer support groups & oncology clinics in three US states	Telephone completion of CDI, RCMAS, IES, PTSD Checklist-civilian version, FES, PRS	FES	No significant differences between groups in symptoms of depression or anxiety. Positive family relationships associated with lower anxiety & depression symptoms in adolescents of parents with cancer. Analysis for both adolescent groups found expressiveness is mediator between family cohesion & anxiety.	USA
Harris 1991 ²⁶	Mixed methods	11	Bereaved adolescents	13-18	Terminal illness, suicide or sudden & unexpected (medical emergency related to underlying condition)	Community resources (most via school counsellors responding to project announcements)	Adolescent followed through the year following parental death using semi structured interviews, DISC (experience of parental death, relationship with deceased, emotional response). Parent interviews. Adolescent: CDI,	Descriptive analysis	For some participants the cause of death remained unclear as information given had been insufficient or distorted. These misunderstandings led to feelings of regret & guilt about their possible role in causing or being unable to prevent the death. Most adolescents believed that emotional expression or discussions of death were unacceptable or potentially overwhelming for their friends	USA

							YSR, IES. Teacher: CBCL. Parent: IES, BDI. Completed at recruitment, 7 & 13 months after bereavement			
Helseth and Ulfseth 2005 ⁶⁰	Qualitative	18	Parents (patients & partners)	4 months – 17 yrs	Cancer: breast, colorectal, melanoma, lymphoma	Parent's medical team	Individual in depth interviews (children's reactions & needs, parental experiences & needs) with ill & healthy parent on 2 occasions	Kvale guidelines	Parents reported best way to manage illness was to be open about situation. Parents expressed strong desire for advice about how to talk to their children about illness & felt this type of support was absent. Talking about the possibility of death was a particular area of concern for parents	Norway
Huizinga, Visser et al. 2005 ³¹	Quantitative	284	Children & adolescents	11-18 & 19-23	Cancer diagnosed 1-5 years prior to study (breast, gynaecological, skin, haematological malignancies)	Single cancer centre	Dutch IES, Dutch YSR, STAI-CH	Not measured	21% of sons & 35% of daughters reported clinically elevated stress response symptoms (IES). Daughters, particularly those whose mothers were ill, reported significantly more intrusion & avoidance symptoms compared to sons. Daughters worry more about their own chances of getting cancer (2/3 of patients in study had female-specific cancer). Perceptions of seriousness of disease related to stress response for daughters, but not for sons	Netherlands
Huizinga, Visser et al. 2005 ³²	Quantitative	212	Children & adolescents	11-18	Cancer diagnosed 1-5 years prior to study (breast, gynaecological, skin, haematological malignancies)	Single cancer centre	Dutch IES, PACS	PACS	Adolescents communicated less openly with mothers who had cancer, relative to population reference group data. Problem communication (with both parents) was related to PTSS in sons & daughters. Parents receiving more intensive treatment associated with more problem communication for sons & less open communication for daughters	Netherlands
Kennedy and Lloyd-Williams 2009 ²⁵	Qualitative	28	11 children ; 10 ill parents; 7 carers	7-18	Advanced cancer	Parents' cancer centre, oncology team, hospice or GP	Semi structured interviews (to identify communication & informational needs of children when parent has cancer). Children chose to be	Constructionist grounded theory approach	All children wanted honest information about their parent's health & treatment; variation with some wanting total honesty & others wanting parents to filter the information according to what they felt able to deal with. Wanted information from a range of sources, including parents, HCP, books, leaflets & online. Concerns about not wanting to upset parents by asking direct questions, lack of access to professionals & age appropriate information. Parents	UK

							interviewed alone or with parents/siblings		identified informing children of their diagnosis & coping with their children's questions as main challenge. Parents did not want to keep secrets & wanted to prepare their children. Reasons for not telling; causing their child distress or not knowing how to tell them	
Kristjanson, Chalmers et al. 2004 ²³	Qualitative	31	Adolescents	12-20 (age at diagnosis <12-18)	Breast cancer; recently diagnosed, stages 1-4, remission & terminal	Purposeful sampling. Cancer centre, palliative care programme, hospital-based support group for children whose parents had cancer	Individual semi structured interviews (experience of parental illness, perception of support & helpful information) communication subscale of FAD. Two focus groups	Constant comparison techniques & FAD	Most salient information adolescents wanted was whether their mother was going to survive. Wanted information about the seriousness of the illness, potential side effects, medical facts, how to help their mother, normal feelings for mothers & young people. Emphasised importance of individually tailored information. Benefitted from time with HCP to provide facts & follow up information, but difficult to access. Information conveyed in private judged easier to understand. Family members sometimes helpful as information interpreters but adolescents felt their parent's management of information could be too controlling & protective	Canada
Lee and Rotheram-Borus 2002 ³⁶	Quantitative	696	301 parents; 395 adolescents	11-18	HIV	HIV social welfare services	5 year longitudinal study. Disclosure classed as: not having occurred (0), if parents told nothing, that they were ill, or chronically ill; or as having occurred (1), if parents disclosed an HIV or AIDS diagnosis, or that they were dying. Parent: BSI, RSES, family stressors & life events, social support, coping styles, perceived stigma. Adolescent: RSES, BSI, PBI	Disclosure status	Disclosure more likely to older children. Mothers disclosed earlier than fathers & more often to daughters than to sons. Disclosure more common among parents with poorer health, larger social networks & those who perceived child experiencing more HIV-related stigma. Following disclosure, adolescents report more problem behaviours in negative family events. Parents perceive their children experience HIV-related stigma following disclosure	USA
Letteney and	Quantitative	88	Mothers	5-18	HIV	HIV Outpatient clinic	Disclosure	Disclosure	No differences in physical or psychological	USA

LaPorte 2004 ⁵²	ve						classed as: 1 = I have disclosed my HIV status to at least one of my children; 2 = I am in the process of disclosing my HIV status; 3 = I have not disclosed my HIV status. PSS, DDM	status	distress between disclosure groups. No differences in marital status, race, religion & employment between mothers who had & had not disclosed HIV status. Mothers who disclosed HIV status had fewer perceptions of HIV-related stigma, more social support & managed HIV-related stigma with strategies other than concealment. Mothers who had not disclosed more likely to feel devalued & discriminated against as result of HIV-positive status & to use secrecy to manage perceived stigma	
Maynard, Patterson et al. 2013 ⁵⁹	Qualitative	15	Young people	14-18 (15.9)	Non terminal cancer diagnosed within last 5 years (breast, mouth & throat, leukaemia, brain & stomach)	Charity or Voluntary organisation	Semi structured interviews (experience of parental diagnosis, emotional needs, parental support & understanding of their experience)	Phenomenological thematic data analysis	Children gauged how much they should worry on their parents' behaviour & used parents as role models for what behaviour was appropriate (e.g. using humour). Wanted parents to be available to talk & answer questions about the diagnosis, treatment & how they were coping. Felt guilty about talking to parents about their feelings, but being invited to talk by parents alleviated guilt. Wanted measured information so not overwhelming. Considerable variation in preferences for level of detail & volume of information	Australia
Murphy, Steers et al. 2001 ²⁷	Quantitative	270	135 mothers ; 135 children	6-11 (8.47)	HIV	HIV clinics	Disclosure classed as: (a) nondisclosure (mothers whose children knew nothing of their illness or serostatus); (b) maternal disclosure (mothers who had told their children personally about their serostatus); (c) other disclosure (children who knew that their mothers were ill or chronically ill and children who knew that their mother had	Disclosure status	Maternal disclosure rate of 30%. Reasons for non-disclosure; child too young to understand, concern child would disclose to others, not knowing how to disclose, concern child would respond negatively to disclosure or lose respect for parent. Mothers who had disclosed status reported higher levels of social support relative to those who had not disclosed. Children of mothers who had disclosed had lower levels of aggressiveness & negative self-esteem relative to the non-disclosure group	USA

							HIV/AIDS but were informed by someone other than the mother). Semi structured interviews. Mother: HDI, Family Functioning (2 subscales), ASSIS, CBCL. Child: CDI, HSC, RCMAS			
Murphy, Roberts et al. 2003 ⁵⁷	Qualitative	47	Mothers who had disclosed to their children	6-11	HIV	Participants enrolled in PACT (Parents and children Coping Together) study	Individual semi structured interviews (process of disclosure & reflections)	Grounded theory approach	Majority of mothers did not regret disclosure to their children. One third of mothers regretted disclosure; regrets categorised into 5 themes: lack of preparation (in terms of timing or planning what to say or when to disclose), timing of disclosure (in relation to child's age, maternal health & concurrent psychosocial stressors), context of disclosure (pertaining to maternal mood), content of disclosure, impact of disclosure on child & desire for professional support for their child	USA
Nam, Fielding et al. 2009 ¹⁰	Qualitative	61	21 parents on ART; 40 children (subset of 24 analysed)	5-18	HIV	Infectious Diseases Care Centre (IDCC) & GP practice	Disclosure criteria not reported. Individual semi structured interviews (disclosure, understanding of illness & treatment)	Disclosure status & grounded theory approach	29% of children had been told about their parents' HIV-positive status; 33% thought to have guessed & 38% believed to be unaware of their parents'. Reasons for disclosure: the child being HIV-positive, rest of the family knowing or the parent becoming very sick. Reasons for not disclosing: believing the child to be too young, not knowing how to address the issue of HIV, or that it would be too painful for the child. Parents concerned other people might find out their status or that child would be stigmatised. Parents described difficulties in addressing issues of HIV & sexual health with their children, preference to leave these topics for schools to address	Botswana
Nelson and While 2002 ³³	Mixed methods	224	144 parents (80 patients, 64 spouses); 80 children	8-16	Breast cancer, leukaemia, gynaecological & testicular cancer	Cancer centres	Individual semi structured interviews. Child: RCMAS, Adapted SPQ. Self-Perception Profile for Children, Social Support Scale for Children. Parent: Rutter	Communication subscale on SPQ, maternal completion of communication measure, content analysis.	Family relationships not associated with children's adjustment. Two main risk factors for poor adjustment in children were low self-esteem & poor adjustment in parent with cancer. Communication about illness not associated with child adjustment so not regarded as risk factor in this study	UK

							Scale A, HADS, MAC, Malaise Inventory, FES, adapted 8-item communication measure. Teacher: Rutter Scale B.			
Niemela, Paananen et al. 2012 ⁵	Quantitative	60,069	Children in Finland born in 1987	Retrospective 21 year review of children who had a parent suffering from cancer	Cancer	Data from Finnish Hospital Discharge Register	Use of inpatient & outpatient psychiatric services recorded on Finnish hospital Discharge Register	Not measured	6.6% of children born in Finland in 1987 had been affected by parental cancer before the age of 21 years old. These children, especially females, had used psychiatric services in either in or outpatient settings significantly more often than their peers during follow up time period. Increased likelihood of psychiatric inpatient care observed for male cohort members when their father had cancer	Finland
Ostrom, Serovich et al. 2006 ⁶⁵	Mixed methods	45	Mothers	5-18 (12.4)	HIV	Longitudinal study; HIV clinics & service organisations	Disclosure classed as: disclosed or non-disclosed (maternal rating). Disclosure measured with a social network screening questionnaire (adapted ASSIS). Reasons for disclosure measured using Likert scales. HIV Stigma Scale	Disclosure status	95% of women did not regret disclosure, wanted to take a lead role in disclosure to their child & make decision based on child's ability to cope with information. Reasons endorsed for disclosure: wanting child to hear diagnosis from mother, child had a right to know, wanting child to understand mother's illness & preparing child for what might happen. Reasons for non-disclosure: wanting child to have a carefree, worry-free childhood, wanting to avoid child's anxiety about mother & protect child from reactions of others. Mothers who experienced stigma reported not disclosing to their children for fear of child telling others	USA
Palin, Armistead et al. 2009 ³⁵	Quantitative	103	Mothers	11-16	HIV	AIDS organisations, hospital, radio broadcasting & word of mouth	Disclosure classed as: disclosed or non-disclosed (maternal rating). Individual interviews (child response to disclosure, disclosure decisions), HESSI, PSI, IBQ PCS, CBCL	Disclosure status	44% of mothers had disclosed to their child; of these mothers half had disclosed within one year of diagnosis & 70% within 2 years of diagnosis. Mothers most commonly endorsed their child's reaction to disclosure as sadness & worry. Disclosure to children significantly predicated externalising but not internalising behaviours, with more externalising behaviour in the group who had been disclosed to	South Africa

Paliokosta, Diareme et al. 2009 ³⁴	Quantitative	157	101 parents; 56 children	4-17	Multiple Sclerosis (duration 2 months-21 years; mean 10.3 years)	Hospital neurology clinics	Disclosure classed as: 1 no information at all; 2 partial information; 3 total disclosure. Individual semi structured interviews. Parent: CBCL, BDI, FAD. Child: YSR, FAD. Functional impairment of patient assessed by doctor using Karnofsky performance Status Scale	Disclosure status	Fathers (both healthy & affected) with higher levels of depression had children who had had more information about parental illness. Parental functional impairment was not associated with communication around illness. Children & adolescents who had 'partial information' had higher scores in social difficulties & internalising behaviours relative to the other two groups. Children's self-rated scores of social problems were significantly higher for those who had had partial information about the parental illness. No correlations between communication around illness & family functioning as assessed by FAD. No relationship between communication & level of parental education	Greece
Phillips and Lewis 2015 ⁵⁸	Qualitative	7	Children	11-15 (13.6)	Stage IV cancer (breast, colorectal, carcinoid)	Parents' medical team	Individual semi structured interviews (experience of parental cancer, emotional and informational needs)	Inductive content analysis	Individual variation in how much & how often wanted to talk about parent's cancer. Difficult to initiate these conversations & sometimes avoided the topic because it was scary. Others found it helpful to talk about cancer with parents	USA
Rosenheim and Reicher 1985 ³⁰	Quantitative	44	Children	6-16	Cancer (to extent that daily functioning was impaired & evident they were ill; Parents undergoing radio or chemo therapy)	Single cancer centre	Parental report of disclosure classed as: informed (explicit naming of cancer) or uninformed. Child: 54 item Anxiety scale for children based on McCandles Costaneda & Palermo (1956)	Disclosure status	Anxiety of the informed group significantly lower than the uninformed group.	Israel
Sheehan, Draucker et al. 2014 ⁷²	Qualitative	56	26 adolescents; 10 ill parents; 20 well parents	12-18 (15)	Cancer-17 ALS-1 Multiple Sclerosis -1 Pulmonary disease-1 vCJD-1 No response-1	Parents' medical team at single hospice	Individual interviews (experience of disclosure)	Constant comparison methods	Outcomes of measured telling were always good; parents proud of how they had disclosed their illness/ imminent death & adolescents satisfied at how disclosure occurred. Participants reported it had engendered trust within the family. Outcomes of skirted telling were generally positive; both parents & adolescents welcomed this approach & did not experience discord. Outcomes of matter of fact telling were neutral; not seen positive or negative, rather	USA

									that these conversations 'occurred'. Outcomes of inconsistent telling were generally negative; adolescents expressed anger & felt they had received too much or not enough information. Parents were aware of their adolescent's dissatisfaction	
Sipsma, Eloff et al. 2013 ³⁷	Quantitative	1018	395 HIV positive mothers ; 114 HIV negative mothers ; 509 children	6-10	HIV	Health clinics	Disclosure classed as: No disclosure; partial; full disclosure. Parent: VABS, CBCL. Child: CDI, RCMAS, BEQI	Disclosure status	7.4% of children had been informed of their mother's HIV positive status & 4.6% partial disclosure. Children of HIV positive mothers who had been told their mother was sick had less internalising & externalising behaviours & improved skills of daily living, compared to children who had been told nothing. No psychological benefit for those explicitly told about HIV compared to the non-disclosure group. Disease severity did not moderate the effect of disclosure on child outcomes. No differences on child reported outcomes	South Africa
Thastum, Johansen et al. 2008 ¹⁷	Qualitative	36	21 children ; 15 parents	8-15 (11)	Cancer (breast, lung, lymph, cervical) disease duration 2-153 months	Parents' hospital-based medical team, GP & community recruitment (patient organisations, newspaper advert)	Individual semi structured interviews (child knowledge of parental illness & emotional experience; parental report of child's knowledge)	Phenomenological analysis	Children felt important to have knowledge about parent's illness. Generally positive in their reports of visiting hospital although some found it frightening or boring. Parents who had not immediately told their children the diagnosis (to protect their child or because of their own feelings) regretted this decision as they felt their child had reacted negatively to the lack of information	Denmark
Thomas, Nyamathi et al. 2009 ⁴⁹	Qualitative	60	Mothers	0-10	HIV/AIDS	STD clinics, HIV clinic & 2 maternity hospitals	Disclosure criteria not reported. 9 focus groups using semi structured interview guide based on Comprehensive Health Seeking & Coping paradigm (issues relating to disclosure to child or family)	Content analysis	Mothers feared disclosure; child may discriminate against them, child's studies adversely affected, or child disclosed details to others. 38% of women felt it best to delay disclosure until children older & able to understand the impact of HIV on the family. Suggestions that counsellor or doctor could make or assist in disclosure	India
Vallerand, Hough et al. 2005 ⁵⁴	Qualitative	54	35 HIV-positive mothers who had disclosed to their children	10-18	HIV	Longitudinal study Living with HIV/AIDS: Mother-child Coping & Adjustment	Individual semi structured interviews (issues related to diagnosis disclosure & child experience of disclosure)	Constant comparative method	Disclosure encouraged open, honest communication & closer relationships between mothers & children. Mothers disclosed when they felt their child was developmentally ready, that the information would help protect their child from infection themselves (through unprotected sex) or when their health declined. Reasons for not	USA

			; 19 children						disclosing: fear of the child not understanding & fear of stigma. Mothers identified some negative effects of disclosure: child's emotional reaction, fears & uncertainty. Mothers & children also raised fears about social ostracisation following disclosure & a need to maintain secrecy around diagnosis	
Withell 2009 ²⁴	Qualitative	10	Bereaved adolescents	13-19	HIV/AIDS	Faith-based HIV/AIDS NGO	Unstructured interviews	Descriptive phenomenological approach	Process of moving from a concealed or disguised reality (no awareness parent was seriously ill; awareness of illness but believed to be treatable) into discerned reality (guess parent dying through observation or intuition), with (for a few) a last minute disclosed reality (disclosure by dying parent). Where information was lacking, children had to construct their own reality of what was really happening to their parent e.g. attributing their parent's death to witchcraft	Uganda
Wood, Chase et al. 2006 ¹¹	Qualitative	97	56 orphans ; 41 adults (including parents & members of wider community)	7-22	HIV	6 NGO sites	Disclosure criteria not reported. Individual interviews (experience of illness & bereavement) & observations, participatory tools including drawings with younger children	Content analysis	Disclosure to children was rare, although adolescents often strongly suspected their parent's symptoms were HIV-related. Orphaned adolescents wanted direct communication with adults about illness & described negative emotional consequences of secrecy. Adults largely mis-interpreted children's withdrawal & quietness as a positive coping strategy	Zimbabwe
Xu, Yan et al. 2007 ⁶³	Qualitative	37	16 caregivers; 5 key informants; 16 children	8-17 (13)	HIV/AIDS (mean time since diagnosis for non-orphans 15 months)	Local community HCPs working with people with HIV	Disclosure criteria not reported. Individual semi structured interviews	Constant comparative method	3 of the 16 children knew their parents had HIV; disclosure prompted by the child seeing some evidence of parental illness. Most caregivers & community informants suggested not telling children to protect them from unpleasant events including discrimination or stigmatisation & psychological distress.	China
Zhao, Li et al. 2015 ⁹	Quantitative	626	Children	6-17 (10.59)	HIV	Community recruitment	Disclosure classed as: disclosed (told by parents about illness in general or HIV specifically) or nondisclosed. children. Survey (awareness of	Disclosure status & content analysis	31% of fathers & 39% of mothers had told their children about their illness. 95% of children who had not been disclosed to by parents were aware of their parent's HIV status from other people or from their own observations.	China

							parental illness & disclosure). CES-DC, CLS, PSS, RSES, SACAA, Enacted stigma, Children Future Expectation Scale, Hopefulness about future, Perceived control over the future			
Zhou, Zhang et al. 2013 ⁵⁶	Qualitative	39	Parents	24% <8 years; 24% 8-14 years. 20% 15-21 years; 28% > 21 years.	HIV	HIV clinics	Disclosure classed as: disclosure and non-disclosure. Open ended interviews (reasons for disclosure, impact of disclosure on child, future disclosure intentions)	Content analysis	77% of parents had not disclosed HIV status to children. Parents who disclosed were older & more likely to disclose to their adult children (mean age of children who had been disclosed to was 27 years, range 11-52 years). Reasons for disclosure: need for emotional & financial support, to prevent their child becoming infected, in response to their child's suspicions. Reasons for non-disclosure: child too young to understand, fear of being stigmatised, fear of being rejected by child, fear of psychological burden to child. 50% of non-disclosing participants did not plan to disclose in the future.	China

ASSIS - Arizona Social Support Interview Schedule

BDI - Beck Depression Inventory

BEQI - Baron Emotional Quotient Inventory (Youth version)

BSI – Brief Symptom Inventory

CBCL – Child Behaviour Checklist

CDI - Children Depression Inventory

CES-DC - Center for Epidemiological Studies Depression Scale for Children

CHQ-MH – Mental health subscale of the Child Health Questionnaire

CLS - Children's Loneliness Scale

DDM - Devaluation-Discrimination Measure

DISC: Diagnostic Interview Schedule for Children

ED – Emergency Department

FAD - Family Assessment Device

FPRQ - Family Peer Relations Questionnaire

FES - Family Environment Scale

GHQ - General Health Questionnaire

HADS: Hospital Anxiety and Depression Scale

HCP – Health Care Professional
HDI – Hamilton Depression inventory
HESSI - Household Economic & Social Status index
HIV SS – HIV Stigma scale
HSC – Hopelessness scale for Children
IBQ - Interaction Behaviour Questionnaire
ICU-intensive Care unit
(C)-IES – (Child) Impact of Events Scale
IPA – Interpretative Phenomenological Analysis
MAC: Mental Adjustment to Cancer scale
MASC: Multidimensional Anxiety Scale
MOHS - Medical Outcomes Health Survey (SF8)
OSSS – Oslo Social Support Scale
PACS - Parent-Adolescent Communication Scale
PBI - Parental Bonding Instrument
PCS - Parenting Convergence Scale
POMS – Profile of Mood States
PPI: Parent Perception Inventory
PRS - Perceived Risk Scale
PSI – Physical Symptoms Inventory
PSS - Perceived Stigma Scale
PTSS - posttraumatic stress symptoms
RCMAS- Revised Children's Manifest Anxiety Scale
RSES – Rosenberg Self Esteem Scale
SMFQ-short: Short Mood & Feelings Questionnaire
SMS – HIV-related Stigma Management Scale
SPQ - Sibling Perception Questionnaire
SACAA - Stigma Against Children Affected by AIDS
STAI-CH - State Trait Anxiety for Children
VABS – Vinel & Adaptive Behaviour Scales
YSR- Youth self-report form

Table 3: Studies evaluating clinical interventions for families when a parent has a life threatening condition

Author	Size of study (n)	Type of participants	Child age range in years (mean)	Parental diagnosis	Method of recruitment	Method	Description of intervention	Measures	How was communication addressed during intervention?	Results	Location
Betancourt, Ng et al. 2017 ⁴⁴ ; Chaudhury, Kirk et al. 2016 ⁴⁵	293	170 children; 123 caregivers	7-17 (11.76)	HIV	Parent's medical team	RCT	Modular, home-based (Family Support Intervention, FSI) to promote parent-child relationships. Aim: to elicit participants' current challenges & apply family's strengths & strategies successfully used in past. Control group: treatment as usual	Adapted & validated for Rwandan context. Child: CES-DC; conduct problems scale; WHODAS-Child, Family Connectedness, Parenting scale adapted from PARQ. Parent: Family Connectedness, parenting scale adapted from PARQ	Intervention aimed to improve communication & understanding	Children who received FSI had fewer symptoms of depression (parental & self-report) at 3 month follow up. No differences between groups on outcomes of child behaviour, child functional impairment, family connectedness or parenting. After HIV disclosure children reported lower levels of parenting & family unity scores; these differences were not seen at 3 month follow up	Rwanda
Christ, Raveis et al. 2005 ⁴¹	184 (plus a comparison group of 556 non bereaved children)	184 families	7-17	Cancer; advanced disease with estimated survival time of 6 months or less	Parent's medical team	RCT	12 month parent-guidance intervention of 6 or more sessions; psychoeducational; enhancing surviving parent's ability to provide care & support for children; provide environment where child felt able to express feelings about loss & maintain consistency & stability in child's environment. Support for parents through their own grief work in order to enhance their capacity to function effectively. Individual interview of child; perceptions of family communication which then informed parent intervention. Control group: telephone monitoring 4-8 weekly; maintain contact with well parent & facilitate referral to appropriate resources. Initiated during parent's terminal cancer & continuing until 6 months after death	Child: CDI; STAI-ch; PPM; IDRCM. Parent: CBCL	Current approaches to communication within family & terminal illness discussed Often included encouraging extensive preparation of children for progression of illness, reviewing specific words & concepts for talking about illness, treatment & death, developmental issues & impact of parental feelings on their ability to understand or meet child's needs	No statistically significant differences between groups on measures of child anxiety or depression, but children of parents in experimental arm a greater decline in scores over time (from initiation of intervention to 6 months post bereavement). Children of parents in experimental arm rated their parent's overall competence & general communication as significantly better during & after the intervention compared to control	USA
Greening 1992 ⁶⁸	51	30 children; 21 parents	4-8	Parents with recurrent or metastatic disease, receiving radiotherapy, chemo therapy or both	Parent's medical team	Evaluation of group by parent participants	Monthly meetings 1.5 hours; parallel children's & parents' groups.	None used	Themes of children's group included information and practical aspects of cancer, including	Parental feedback very positive. Parents indicated they would not attend a support group for themselves, but were highly motivated to engage in any support available for their child. Parents attended group due to concerns about their child's future & a desire for information & reassurance from professionals. Parents did not expect to benefit	USA

									visiting the hospital & information about treatment & equipment. Session on feelings & emotional expression. Parallel, facilitated, parent sessions included discussion about what to tell children about parental illness & developmental understanding	themselves, but found it a valuable experience	
Lewis, Brandt et al. 2015 ³⁸	352	176 mothers; 176 children	8-12	Diagnosed within 6 months with Stage 0-III breast cancer	Parents' medical team in 6 US states; community cancer centres & self-referral	RCT	5 fully scripted patient education counselling sessions delivered at 2 week intervals to mother; interactive booklet about breast cancer read by mother to child; mother's workbook containing didactic text, in-session & at-home assignments completed by mother & child; child completed activity booklet about how child deals with stress. Access to patient educator via pager if required. Control group: mothers received printed booklet focussing on ways to support child about breast cancer; short (<10 mins) follow up call to review key points in booklet	Mother: CESDS; STAI; CSES; FPRS; PSC. Child: CBCL; RCMAS; CDI (maternal & child report)	Developing mother's listening skills; understanding child's experience as distinct from her own (strategies to prevent emotionally flooding child); attending to child's thoughts, feelings & concerns; strategies to support child who may be reluctant to share their feelings	Significant improvements in depression, parenting skills & child behavioural-emotional adjustment and depression relative to controls at 2 month follow up. At 1year post intervention, children of mothers in the experimental arm remained significantly less depressed compared to controls (child & parent report). Intervention did not affect parenting self-efficacy or maternal anxiety	USA
Murphy, Armistead et al. 2011 ³⁹	160	80 mothers; 80 children	6-12 (8.7)	HIV	HIV/AIDS service organisations	RCT	Standard care plus 3 sessions; child development, pros & cons of disclosure, improving mother-child communication, behavioural practice for disclosure. Control group: Standard care	Mother: DSE; FRQ; PACS; PSI; RMHI; MOS SF-36; FC from FFS Child: CDI, PHCSCS; IPPA	Intervention targeted at enhancing familial communication & parenting skills specifically around disclosure, increasing readiness to disclose /disclosure	33% of intervention group & 7% of control group disclosed during course of study. Mothers in intervention group had increased disclosure self-efficacy, increased parent-child communication & improved maternal emotional functioning. Children of mothers in the intervention group showed reductions in depression & anxiety & increases in happiness (regardless of disclosure status). Intervention helpful for mental health indicators, even if mothers did not disclose	USA
O'Malley, Beima-Sofie et	81	46 caregivers; 35 HCPs	7-15	HIV	HIV clinics	Evaluation of intervention	Book with cartoons to facilitate caregivers & HCPs	Semi structured interviews &	Disclosure of HIV book	Caregivers & HCPs found book helpful in disclosing the child's HIV status & increasing	Namibia

al. 2015 ⁷⁰							gradual disclose. Includes information on medication and HIV	questionnaires regarding HCPs' confidence in managing HIV disclosure & experience of implementing intervention	sharing	their skills to facilitate their child's medication adherence. HCPs reported book reduced caregivers' reluctance to disclose	
Rochat, Mkwanazi et al. 2013 ⁷⁸	48	24 mothers; 24 children	6-9 (7.8)	HIV	Re-enrolled from previous study conducted in the Africa Centre	Pilot study to establish feasibility and acceptability of the Amagugu intervention	6 session training intervention led by community worker for mothers & their children; written materials & games to prepare for & support maternal HIV disclosure to uninfected children; clinic and HCP training on child friendly clinical spaces	Qualitative measures of participants' perceptions of intervention, self-reported maternal health prior disclosure experience, disclosure level & impact on family. Disclosure classed as Full disclosure using the words HIV; Partial disclosure excludes the words HIV & substitute virus or illness	Amagugu Intervention: Communication using materials such as board games, playing cards, storybooks assisted parents in talking about HIV in a structured and clear way	All mothers chose to disclose something about their illness; half achieving full disclosure. Mothers' concerns about disclosure included child's emotional distress, risk of child disclosing to other people & managing child's questions about HIV. Children's reaction to disclosure (maternal report): 14 children calm & confident, 8 confused & 2 distressed or fearful. Materials were seen as culturally sensitive & helpful by community workers and stakeholders.	South Africa
Rochat, Arteché et al. 2014 ⁵³ and 2015 ⁴⁷	562	281 mothers; 281 children	6-10	HIV	Re-enrolled from previous study conducted in the Africa Centre	Uncontrolled pre & post intervention evaluative of the Amagugu Intervention.	6 sessions at home; printed materials & child-friendly activities to prepare for & support maternal HIV disclosure to uninfected children	Mother: took child to clinic visit, completed child care plan, discussed care plan with child, legal guardian appointed and timing, GHQ, PSI, CBCL. Process evaluation data on maternal and child experiences of intervention. Disclosure classed as Full disclosure using the words HIV; Partial disclosure excludes the words HIV & substitute virus or illness; No disclosure.	Amagugu intervention	60% of mothers 'fully disclosed' & 40% 'partially disclosed' their HIV status to their child. Mothers who perceived their health to be excellent were less likely to fully disclose compared to those considering their health to be poorer. More likely to fully disclose if in current partnership. Most children reacted calmly to full or partial diagnosis (maternal report). Children whose mothers fully disclosed were significantly more likely to react surprised & less likely to react confused. Mothers much more likely to report their child's reaction to the diagnosis as 'emotional'. Compared to partial disclosure, full disclosure associated with more children asking questions about maternal death. Maternal reported psychological distress & parenting stress decreased following intervention. Reduction in child emotional & behaviour difficulties (maternal report). Reductions in scores were not moderated by the level of disclosure (full/partial).	South Africa
Rochat, Mitchell et al. 2017 ⁷³	562	281 mothers; 281 children	6-10	HIV	Secondary analysis of evaluation data in Rochat et al 2014 and 2015	Mixed methods	See Rochat et al 2014 and 2015	GHQ and parenting stress PSI; Child mental health CBCL. Maternal reported data on: Most and least enjoyable parts of intervention; question children asked post disclosure; child emotional reactions to disclosure; child	Amagugu Intervention	61/281 children asked death related questions; most concerned about the threat of death, their mother's survival & prior family deaths. Children more likely to ask a death related question if their initial response had been fearful & their mother had regular income. Full disclosure led to increased odds of questions about death. Children who discussed the possibility of death with parents showed improved scores in post intervention evaluation (when controlling for baseline CBCL). Discussion of death did not increase psychological problems. Evidence that many children were aware of the effects of HIV	South Africa

								IQ (Ravens) Full disclosure using the words HIV; Partial disclosure using the words virus or illness.		on family, hospitalisation, and deaths.	
Rochat, Stein et al. 2017 ⁴³	928	464 mothers; 464 children	6-10	HIV	Primary healthcare facilities	RCT	Intervention group: 6 sessions at home; printed materials & child-friendly activities to prepare for & support maternal HIV disclosure to uninfected children. Control group: Enhanced standard of care of one clinic based counselling session.	Mother: PHQ-9, PSI, GAD-7, FAD, CBCL, took child to clinic visit, completed child care plan, discussed care plan with child, legal guardian appointed and timing. Disclosure classed as: Full disclosure using the words HIV; Partial disclosure excludes the words HIV & substitute virus or illness; No disclosure.	Amagugu Intervention	Higher rates of disclosure (partial or full) in intervention group (n=204 [87%]) compared to control (n=128 [56%]). Full disclosure was also more common in intervention group (n=150 [64%]) compared to control (n=98 [43%]) and time to disclosure was significantly shorter in the intervention group. Intervention participants were more likely to take their child to visit the clinic, develop care plan and appoint a legal guardian. No significant differences in mental health in either parents or children between groups. Significant improvements in the parent-child relationship in the intervention group.	South Africa
Rotheram-Borus, Lee et al. 2001 ⁴²	719	307 parents; 412 adolescents	11-18 (14.8)	HIV	HIV /AIDS services database	RCT comparing group intervention with standard care	24 sessions focused on emotional reactions to illness, stigma, disclosure, conflict resolution & future planning. Attended by parents & adolescents (parallel groups)	Parent: BSI, Coping with Illness Questionnaire (5 subscales), custody plan parameters, count of multiple problem behaviours. Adolescent: BSI, count of multiple problem behaviours, conduct problems, RSES	Intervention group modules	Intervention group had significantly lower levels of emotional distress & family related stressors, fewer behavioural problems, higher self-esteem at 24 months follow up compared to control group. Parents reported lower levels of emotional distress & fewer problem behaviours. High levels of disclosure (both at baseline & 24 month follow up), similar for both groups.	USA
Thastum, Munch-Hansen et al. 2006 ⁴⁰	75	24 mothers; 17 fathers; 34 children	8-15 (11.4)	Cancer	Somatically Ill Parents (COSIP) study	Evaluation of short term preventative counselling project	5-6 sessions (mean 4.75 sessions per family) focused on illness-related problems. Attended by family members, usually at home. Children also offered group counselling with other children participating in project. Control group: TAU (families declined counselling)	Parent: BDI; FAD Child: BYI, IPPA, QMHRQoLCA. Evaluation of intervention by parents, children and therapists through semi structured interviews about experience of intervention & adapted version of Therapy Evaluation Questionnaire	Aims of intervention: facilitate open communication about illness, increase parental emotional availability, support parents in age-appropriate communication of factual & emotional issues related to illness, enhance children's cognitive understanding of parental illness, recognise &	Significant decrease in depression for mothers & increase in family functioning (Communication & Affective Responsiveness subscales) for parents after the intervention. Significant decrease in depression scores for children after the intervention. Parents' sought counselling to address concerns about how to support their children, difficulties in communication about problematic or emotional aspects of illness & conflict within family. Parents & children reported counselling helpful in terms of understanding emotional reactions of other family members. Counsellors' highlighted lack of open sharing of illness-related emotions within families, resulting in parental insecurity about how children felt, or whether children had someone who they could share their worries with. Content of counselling sessions address these concerns. Intervention rated positively by families	Denmark

									accept needs & feelings, family coping & parental competence in parenting		
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BDI: Beck Depression Inventory
 BYI: Beck Youth Inventory
 CDI: Children's Depression Inventory
 CES-DS: Center for Epidemiological Studies Depression Scale
 CSES: Cancer Self-Efficacy Scale
 DSE: Disclosure Self-efficacy
 EORTCQoLQ: European Organisation for Research & Treatment of Cancer Quality of Life Questionnaire
 FAD: McMaster Family Assessment Device
 FC from FFS: Family Cohesion subscale from Family Functioning Scale
 FPRS: Family-Peer Relationship Scale
 FRQ: Family Routines Questionnaire
 GCQ: General Communication Questionnaire
 GHQ: General Health Questionnaire
 IAS: Illness Attitudes Scale
 IBQ: Interaction Behaviour Questionnaire
 IDRCM: Illness & Death-related Communication Measure
 IPPA: Inventory of Parent & Peer Attachment
 IQoLCA: Inventory for Quality of Life in Children & Adolescents
 MOS SF-36: Medical Outcome Study Short Form 36
 PACS: Parent-Adolescent Communication Scale
 PARQ: Parental Acceptance-Rejection Questionnaire
 PHCSCS: Piers-Harris Children's Self Concept Scale
 PSC: Parenting Skills Checklist
 PSI: Parenting Stress Index
 PPM: Perception of Parenting Measure
 RCMAS: Revised Children's Manifest Anxiety Scale
 RMHI: Rand Mental Health Inventory
 RSES – Rosenberg Self Esteem Scale
 SC-90: Symptoms Checklist-90 for adults
 SC: Sense of Coherence
 SDQ: Strengths & Difficulties Questionnaire
 STAI: Spielberger State-Trait Anxiety Inventory
 STAI-ch: State-Trait Anxiety Inventory for Children
 QMHRQoLCA: Questionnaire for Measuring Health-related Quality of Life in Children & Adolescents
 WHODAS-Child: World Health Organisation Disability Assessment Schedule for Children