

Appendix 4: Systematic mapping data extraction table

Abbreviations

CYP : children and young people

Paed : paediatric

Multiple papers on same study marked with the same superscript number

Study	Methods	Sample characteristics	Findings which contribute to synthesis question of what makes 'good' or 'bad' LTC (close to orig text)
Condition, population or service Aims/ question Rationale	Design Recruitment Selection Exclusion Data collection Data analysis Reliability + - eg theories clear; data management software; team discussion of coding/dble coding; methods reporting; discussion of changes in context Validity + - eg taping; pilots; participants at ease; triangulation; thick description	Participants /sample size Location Children's age range Gender SES Ethnicity	

<p>1. Edgecombe et al 2010</p> <p>Uncontrolled severe asthma Aim: to understand [YP's] experience of living with uncontrolled severe asthma Rationale – despite 'a prescription of corticosteroids and bronchodilators [yp] still experience symptoms... likely to be related both to asthma severity and developmental characteristics of adol such as risk-taking behaviour. These adol face additional diffs in achieving the normal psychological and social developmental tasks of adol such as gaining identity, independence and autonomy. [Understanding their views] will enable us to propose ways of improving clinical management' p985</p>	<p>Design - qualitative Recruitment via paed respiratory clinics Selection self selecting from all in sample frame, then purposive (not clear) Data collection – in-depth semi-structured interviews Data analysis Reliability + double coding/discussion; explicit theory of adolescence - Validity + taped interviews, flexible questions, clarity re confidentiality, negative case analysis - Interviewed by med student in clinic; asked them to fill out QoL measure as well; - conclusions don't match aims -no engagement with critiques of developmentalist approaches</p>	<p>Participants : 22 CYP Location: Southampton, Portsmouth and Isle of Wight areas Children's age 11-18yr Gender 6 girls, 16 boys SES N/K Ethnicity N/K Exclusions yp with non-atopic comorbidities which could affect QoL</p>	<p>YP disliked - frequent changes of medicines - find confusing (authors feels may account for some 'unintentional non-adherence') YP ambivalent about paed models of care Disliked being with young children and parents' presence if they had confidential concerns to discuss Though relied on parents to report symptoms, remember what was agreed and 'translate' medical terms and many were nervous of attending on their own, one felt doctor wouldn't want to see her alone anyway. CONC 'this group has poor adherence... underlying this are incorrect beliefs about medicines in terms of their purpose and adverse effects, failure to remember treatment, lack of motivation or competing priorities... these issues may in part reflect the less than ideal relationship that this study suggests adolescents have with their health professionals... many did not take responsibility for interacting with HCP...</p>
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<p>2. Lyte et al 2007</p> <p>Asthma Aims: present an overview of paed asthma management in a UK primary care trust with respect to organisation and perceptions of stakeholder, parents and CYP needs. Rationale – fragmentation of care over prim, secondary, school and community services</p>	<p>Design Case study Recruitment via GP surgeries in one PCT Selection purposive on GP structuring of system of care and level of interest in paed asthma Data collection Interviews, observations of review appts and asthma related documentation Data analysis Framework Reliability + double coding -</p>	<p>Participants 18 CYP 16 parents 14 prac nurses 14 GP Location practices in 'one PCT' with wide range of different levels of deprivation Children's age N/K</p>	<p>Improving practice nurse care will require - a pro-active recall system to ensure regular reviews inc assessment, revising management plans and health promotion/education; - developing PN understanding of paediatric work beyond a focus on communicating with children to the wider complexities of work across families so that children don't feel left out of consultations and families feel their needs are being met (perhaps support not just on asthma from the asthma clinical nurse specialists (CNSs) but also on family centred care (FCC). CONC – responsibility for management needs to be</p>
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and concerns about practise nurses' depth of knowledge on paed asthma (no paed training)	Validity + taped, full transcription - Venue for interviews and reltion with interviewer N/K;	Gender N/K SES see location Ethnicity N/K	formalised, and PN role receive greater education / prep for being proactive and providing
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<p>3. Newbould, Francis and Smith ADC 2007</p> <p>Asthma/diabetes</p> <p>Aims: to examine experiences and concerns of YP and their parents re management of medicines at school</p> <p>Rationale – ‘despite guidance from government and creation of school policies, difficulties surrounding medication and condition management in schools are still prevalent’ p1078</p>	<p>Design Not explicit Recruitment: GP surgeries Selection random surgeries, N/K how CYP selected Data collection: face to face semi structured interviews at home Data analysis established qual analytical procedures Reliability + - Validity + interviews at home; taped; full transcription; - not qual sample strategy: ‘designed to obtain representative sample primary care sample of yp’</p>	<p>Participants 69 YP (43 asthma; 26 diabetes) and parents Location ‘contrasting areas’ in SE Eng Children’s age 8-15 yrs Gender 39 boys, 30 girls SES only 11 parents reported not owning home Ethnicity: 3 parents ‘non-white’</p>	<p>YP need support from HCP around</p> <ul style="list-style-type: none"> - access to their medicines - policies could be a hindrance eg having to keep inhalers elsewhere (‘I’d have to walk all the way to the office’) - other structures eg snacks being forbidden, timing of school lunches, nowhere private to do injections - teachers being disbelieving and unsympathetic (parents also felt this, and that teachers lacked knowledge). <p>Parents need support around concerns about:</p> <ul style="list-style-type: none"> - medicines being stored away from the classroom which could make access diff in a crisis; - teachers undermining regimen eg not wanting child to test blood sugar levels; <p>-liaison witt teachers a much greater challenge in secondary school cos of having more than one teacher</p> <p>CONC protocols in schools should be tailored to YP needs and indiv conditions, devised in partnership with YP, parents and school. Authors note guidance on medicines in schools (DH, 2004 NSF) doesn’t clarify teachers’ position if they must help yp with a medical difficulty.</p>
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<p>4. Forsey et al 2013</p> <p>Leukaemia</p> <p>Aim: How might doctors and nurses accounts of managing the emotional care of parents of children with leukaemia inform training and policy</p> <p>Rationale – guidelines encourage HCP to discuss patients’ personal/emotional experiences’ tho evidence suggests they are not doing this – ‘there seems to be a gap between policy and practice’ p260</p>	<p>Design ‘qualitative interviews’ Recruitment: via 6 oncology /haematology treatment centres in UK Selection: Purposive across centrality of role in child’s care; equal across centres and by profession and both community and hospital nurses Data collection Audio-recorded qualitative interviews at 2 time points Data analysis Constant comparative Reliability + multiple investigators involved in development of themes arising from data - Validity + taped; flexible interviews; verbatim transcripts -authors assume higher degree of generalizability than justified by study design</p>	<p>Participants 30 doctors and nurses Location UK wide Sample size 30 Gender mainly male doctors and women nurses SES doc/nurses Ethnicity n/k</p>	<p>Doctors thought their best contribution to emotional support is to focus on potential for cure in order ‘to keep the family together so they can function tomorrow’; and not try to elicit parents’ concerns or fears (seen as nurses’ work: they are at ‘the right place at the right time’ eg home visits, night shifts, when there is a more ‘relaxed environment.’). Felt it best to use their ‘authority’ as doctors to <i>prevent</i> an ‘inappropriate’ ‘emotional’ , relationship as they may need to challenge parents in children’s best interests eg re adherence.</p> <p>Nurses thought they should develop emotional relationships, share details of their lives and offer emotional support on demand (they can phone you up’); though could feel guilty about not having capacity to provide high levels of both emotional and physical care and feel overwhelming/stressful when families too emotionally dependent.</p> <p>CONC: we need to know parents perspectives but perhaps guidelines which require an emotional as well as instrumental approach by doctors may need revision</p>
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<p>5. Lowe et al 2008</p> <p>Haem/Oncology</p> <p>Aim: to examine families’ views on care in a paed haematology/ oncology day care unit</p>	<p>Design Focus gps Recruitment: via unit Selection: self selecting: families receiving care</p>	<p>P’pants 16 parents (13 mothers and 3 fathers) Location</p>	<p>Parents disliked:</p> <ul style="list-style-type: none"> - when play specialist diff to access as ‘too stretched’ - toys ‘dirty’, physical environment ‘cramped, inhuman, frightening... like a cattle market’ p3164 - long waits for chemo, consultations and prescriptions - both in local and primary treatment centres), though explanations could help. - systems for prioritising patients for general anaesthetic were debated as some felt this should be in order of arrival, others that those receiving steroid
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<p>Rationale – with increasing ‘pressure on inpatient beds in primary treatment centres’, greater number of CYP care now is shared between the primary treatment centre and their local hospital which ‘is not problematic if...services are designed to meet families’ needs and where there is a seamless service’ btw the two. The patient journey thru the unit was mapped from HCP perspectives but it was felt ‘the voice of children and families’ was missing. p 3161</p>	<p>for acute lym leukaemia (or within 6 mths of completion) Data collection: focus grps of 3-5 people Data analysis thematic Reliability + researchers discussed each other’s analysis with one another - Validity + taped; notes; - groups took place ‘off the ward’</p>	<p>London SES n/k Ethnicity n/k</p>	<p>treatment get priority (great hunger) - some felt rushed in such a busy environment and lacked confidence or time to ask questions - unfamiliar faces eg rotation of junior doctors - problems with liaison between local hospitals and primary treatment centres - local hospitals relied on them to pick up things that get missed, and they didn’t necessarily have the knowledge of protocols to do that. Parents valued: - help learning procedures/routines of the unit at the same time as having to deal with disbelief at diagnosis - liked when staff went out of their way to familiarise them/ do introductions, and the CNS role in connecting home to hospital – also wanted someone available who felt more approachable such as an experienced parent volunteering; an info board with outline of routines – and, before their child transferred from inpatient care, a visit with introductions to the day care unit; - toys and play specialists crucial to their child’s experience - information overload at time of diagnosis so needed profs to ‘continually build on and scaffold info’; they especially valued written info - roles and mechanisms to support liaison between local hospital and this prim treatment centre eg new CNS role; the ‘family-held shared care record’ which held contact details of hospitals, treatments/side effects, and advice eg on anaesthetics, infections, schooling, home life and links to other info CONC – environment and communication were the main problems and CNS role was felt to ‘make a qualitative difference’</p>
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<p>6. Allen et al 2011¹ Diabetes (transition) Aim: to explore the experiences of YP and their carers during transition from child to adult diabetes services</p> <p>Rationale – YP life transitions are not linear, no longer move from ‘a state of dependence to independence’, and care transition take place at time of multiple other life transitions, plus difficulties in control from physiological change</p>	<p>Design Longitudinal qual case studies in 5 different diabetes services Recruitment via ‘service providers’ Selection ‘appropriately placed service providers’ and purposive selection of yp by gender and position in process of transfer Data collection 3 x semi-structured interviews with yp and with mothers over 12-18mths (other party occasionally present during interview) Data analysis thematic Reliability + Identifies ideas from Strauss’ account of illness trajectory as underpinning understanding of yp’s accounts; data management software used - Validity + flexible approach to interviews; full transcription, most interviews at home - Authors report diffs recruiting yp</p>	<p>Participants 46 CYP and 39 mothers Location N/K (UK) Children’s age 13-22 yrs Gender 23 girls; 23 boys SES n/k Ethnicity N/K</p>	<p>Problem - health professionals seem to encourage a shift to lone consultation faster than yp and their parents choose when this is left up to them - and at a time when mothers feel yp’s needs are very high (because of multiple other shifts and transitions at this time of their lives) Some mothers felt shifts to lone consultation lead to discontinuities of information and undermine their ability to continue to support their child into young adulthood...</p> <p>Good care would reflect how the lives of YP are characterised by interdependencies... authors feel there is a need to develop service structures that recognise the continuing role played by mothers in the diabetes care of young adults eg in a few services a written report of the consultation was provided to parents of yp under 16 years who had moved to lone consulting (authors note that 16 years and over there are issues with confidentiality in this approach); in other services parents attended for part of the consultation; in another, the DSN made clear she would engage with parents as well (tho most didn’t contact her, perhaps believing they won’t be welcome). CONC The ‘individualised focus of adult services does not reflect the realities of yp’s lives’p999</p>
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<p>7. Allen et al 2012¹ Diabetes (transition) Aims: To</p>	<p>Design case study Recruitment: via diabetes services in England in the Directory of Diabetes Care Selection: at service level, purposive by transition arrangements; yp by gender and</p>	<p>P’pants 38 HCP; 46 YP and 39 carers in case studies; 82 YP and carers surveyed</p>	<p>Users wanted (nearly verbatim) transition care that is - a) <i>Relational</i> - ‘an ongoing therapeutic relationship with one or more providers [who] understand the fabric of individual’s lives’ esp so, for example, ‘deteriorating control is understood in the context of individual’s care trajectory rather than as non-compliance’ p143; ‘consultation style and interpersonal skills were highly consequential for the exp of yp’ p 144 b) <i>Longitudinal</i> - ‘uninterrupted relationships with providers over time, consistent with need’ These in turn are supported if care has the following 2 characteristics:</p>
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<p>id mechanisms that help smooth transition, service components thru which these can be achieved and their interrelations</p> <p>Rationale – gap btw g'lines and 'evidence to inform service commissioning' p141</p>	<p>transition arrangements</p> <p>Data collection: interviews with HCP with 'selected observations'; 46 case studies with yp and families comprising 3 interviews over a year/18mths including discussion of medical record; survey with 82 YP and carers; costs analysis</p> <p>Data analysis of interviews with HCP and families not reported</p> <p>Reliability</p> <p>+ -</p> <p>Validity</p> <p>+ flexible schedules to take into account emerging analysis; taped interviews - not clear if 'selected observations' means during HCP interviews or of something else</p>	<p>Location English diabetes services</p> <p>Gender/SES/Ethnicity N/K</p>	<p>c) <i>Flexible</i> - ie responsive to yp's needs – many adult services provided more clinics, access to on-call nurses and email mentoring to new yp; or flexible approaches to lone consulting so yp got time with parents and also alone in consultations; yp wanted one-stop shop info/education events at same time as clinics, not enthusiastic about formal education events outside clinic (though staff were), nor peer based support; and service funding arrangement should facilitate young adults' needs for higher levels of on-going support</p> <p>d) <i>Management continuity</i> - through a common purpose and treatment plan: nursing teams were reported better at liaising across adult/child divide, medics less so; mothers could do a lot of work ensuring this tho found difficult where they no longer attended appt with yp after transfer; one service improved management continuity via appointment of a 'transition nurse' to span both services</p> <p>Users also wanted</p> <p>e) <i>Cultural continuity</i> - Seamless progression from child to adult service culture – services led by clinicians with a commitment to adol had high cultural continuity – so clinical leadership is essential to getting continuity here</p> <p>f) <i>Developmental continuity</i>- Care that proactively supports yp to develop physically, psychologically and socially (usually info round 'risk issues' like alcohol, pregnancy, drugs etc) : in services with graduated transfer could work flexibly in relation to yp's needs (which they valued) - rather than all at once as tended to happen in models with discrete one-step transfer</p> <p>g) <i>Informational continuity</i> - Provision of info to prepare for new service arrangements must be especially high where a) and b) are lacking, eg where there is a complete rather than graduated transfer to new clinicians; and also to explain the rationale for joint adult/paed clinics which yp report confusing</p> <p>Authors found services with high levels of a) and b) (eg small, co-located teams or where clinicians don't change) needed only informal, low cost informational and management continuity mechanisms, whereas services with low a) + b) needed to invest in more formal mechanisms to support transfer, eg good written information</p> <p>CONC- Authors highlight synergy with other evidence on the importance of acknowledging young people's 'life situation' and problems with 'the neglect of carers' p146</p> <p>'while the progression to lone consulting was a key developmental milestone for young people, many mothers felt cut off from the process' p146:</p>
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<p>8. Curtis-Tyler 2012</p> <p>Diabetes</p> <p>To explore experiences of children 10 years or younger living with T1D with a view to identifying levers and barriers to children's contribution to their clinical care</p> <p>Rationale – patients' views are important in identifying the best options for care tho achieving this in practice has proved difficult</p>	<p>Design In-depth qual</p> <p>Recruitment: 2 outpatient clinics</p> <p>Selection: ch under 11 yrs, self-selecting</p> <p>Data collection – home visits, discussion groups, observation in clinic</p> <p>Data analysis constant comparative</p> <p>Reliability + explicit about understandings of children/childhood; data management software -</p> <p>Validity + home visits; taped, full transcription, negative case analysis -</p>	<p>Participants 17 children</p> <p>Location: Large multicultural city</p> <p>Sample size 17</p> <p>Children's age 4-10</p> <p>Gender 8 girls, 9 boys</p> <p>SES NK</p> <p>Ethnicity 6 Somali; 5 White british/english 1 Lithuanian, 2 Arabic, 2 African, 1 Bengali British</p>	<p>Problem: in contrast to their sense of being key players in their day to day care at home, children felt their position in clinic was peripheral, that they had nothing useful to contribute. They were excluded from discussions of illness, they and parents had little control over the timing, pace and direction of interaction, the tightly focussed question and answer format was at odds with discursive approaches favoured at home, and a bio-medical model of illness fragmented experiences into physiological, social and emotional components.</p> <p>Conc - if clinicians want to hear from children they will need to provide a convincing rationale so questions are not perceived as a test; engage w/ children's strong experiential understandings of their condition by framing questions in terms of activities and sensations, and try to redress generational prof/lay imbalance of power by demonstrating respect and attention. However if the mainly physiological focus of consultations acts to protect families from prof surveillance, it may prove difficult to shift.</p>
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<p>9. Curtis-Tyler 2011</p> <p>Asthma/diabetes</p> <p>Aim to identify from a synthesis of studies</p>	<p>Design Qual synthesis</p> <p>Recruitment/Sources: 8 health and social care databases, ref list searches, consultation with first authors/field experts</p> <p>Selection: qual studies of ch (10 yrs and</p>	<p>Participants : 14 papers</p> <p>Location both UK/USA</p> <p>Sample size</p> <p>Children's age 10 years or younger</p> <p>Gender/SES N/K (review)</p>	<p>PROB: One study observed younger children especially seemed to be excluded from discussion of their illness in clinic. Across studies children reported difficulties managing asthma or diabetes at school because of lack of access to</p>
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<p>on children's experiences of living with asthma or diabetes, levers and barriers to patient-centred care with children</p> <p>Rationale – gap in the evidence about how to achieve children's involvement in clinical care</p>	<p>younger) experiences of living with asthma or diab</p> <p>Data collection N/A</p> <p>Data analysis / synthesis: narrative synthesis</p> <p>Reliability</p> <p>+ data management software used; understandings of childhood explicit</p> <p>-</p> <p>Validity</p> <p>+ study findings presented in context of QA of methods</p> <p>-</p>	<p>Ethnicity mainly white or unspecified</p>	<p>medicines, school routines which threatened their valued sense of 'sameness' to peers</p> <p>CONC Action on levers identified may prove difficult because they involve 'a move away from medicine's historical focus on children's developing competencies to engage rather with their social realities from the earliest ages' p540</p>
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<p>10. Dovey-Pearce et al 2005</p> <p>Diabetes</p> <p>To describe and understand considered opinions of young adults with diabetes about secondary services</p> <p>Rationale – YP are broadening their focus from 'tasks of childhood (eg friendships, academic success and community conduct) to include emerging tasks of adulthood (work, intimate relationships, other future life-goals ...they must receive developmentally appropriate support that takes into acct how their health care goals fit with their other life goals' p410</p>	<p>Design Qual</p> <p>Recruitment via specialist diab service</p> <p>Selection self-selecting from pop of 16-25 yrs olds w T1 or T2 using secondary care</p> <p>Exclusions diagnosed less than 6 mths, Learning disabilities (also apparently autism)</p> <p>Data collection semi structured interviews and, having had feedback, focus gp discussion of findings</p> <p>Data analysis framework</p> <p>Reliability</p> <p>+ explicit theory of adolescence</p> <p>Validity</p> <p>+ taped and full transcription; schedule amended twice; double coding</p> <p>- no engagement with critiques of developmentalist approaches</p>	<p>Participants 19 young adults with diabetes</p> <p>Location NE Eng</p> <p>Children's age 16-25yrs</p> <p>Gender 11 girls, 8 boys</p> <p>SES/Ethnicity N/K</p>	<p>YP disliked:</p> <p>At diagnosis - information overload, wards with much older adults, insensitive staff</p> <p>Secondary care - not knowing which clinician they would see in clinic, having to repeatedly share same information, not being involved in consultations, overly directive or conflicting advice with little relevance to individual situation, insensitive personal questions/giving bad news, breaches of confidentiality, feeling unable to ask questions/rushed, having to suppress distress, formality, lack of civility, poor communication between services and age inappropriate communication: 'I'll just sit and listen... and go home. I think, what's the point'</p> <p>She said you should do this and that and she was reading from a text book [but] it's in a text book and it might not exactly apply to me. I might do all that and end up coming into hospital' P409</p> <p>'[The doctor] used to talk to me like I was a baby [and] to my mum as though I wasn't there' p 414</p> <p>YP could feel passive recipients eg re move to adult care 'manhandled as a piece of meat with no respect'; that because of their age they don't deserve as much time/attention as older people, that they are culpable for not controlling their condition 'for the future', or that information they are given isn't actually relevant to someone their age.</p> <p>Disliked activities shared with others with diabetes;</p> <p>YP would like:</p> <p>Some thought age-banded clinics could be helpful</p> <p>Interactions with staff seemed to be YP overriding concern (over for example, travel or clinic times), positive ones characterised by consistency, civility, rapport, listening, involvement in the consultation, choices, non-judgemental approach, encouraging feedback, facilitating coping skills and access to specialist information, whole person care facilitated by the MDT and age appropriate shifts in consultation style.</p> <p>CONC – 'Bringing together a yp with a chronic condition who is still experimenting, exploring and keeping some of their options open with a healthcare system that expects engagement, partnership and adherence that will last a lifetime is an unlikely marriage... developmental tasks of adulthood [include] taking responsibility for self-care ... yp need to be supported to acquire the requisite skills, knowledge and motivation needed to be committed partners in their healthcare'' p417</p> <p>'key requirements [are] staff consistency and civility, and navigable clinic structures... relevant information and support p417</p>
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<p>11. Eiser et al 2013</p> <p>Diabetes</p> <p>To use MRC guidelines on complex interventions to develop an intervention to improve physical and psychological health among yp with T1D</p>	<p>Design MRC guidelines for devp a complex intervention</p> <p>Recruitment via young adult clinic (16-21 yrs)</p> <p>Selection self selecting</p> <p>Data collection interviews w staff, YP and carers on views of care; audit of medical records</p>	<p>Participants 13 staff, 27 YP, 18 parents</p> <p>Location Sheffield</p> <p>Children's age 16-21yrs</p>	<p>Staff described difficulties communicating with YP and using different approaches with yp which yp reported as inconsistent.</p> <p>YP disliked</p> <p>- abstract information which didn't take account of their lifestyle.</p> <p>- an emphasis on hba1c at the expense of their concerns</p>
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<p>Rationale – poor success of previous interventions, complex nature of care and impact on well-being and wider life; challenge of adjusting to life-threatening illness at this life stage, dependence on wider family/social support, rising incidence and link bwn early control and morbidities</p>	<p>and survey of YP self reported anxiety, depression + diab related distress; searches for existing evidence on how to improve diab health in young adults Data analysis n/k Reliability + - Validity + -</p>	<p>Gender/SES/Ethnicity n/k</p>	<p>around how to integrate self care into their daily lives. Parents disliked - feeling sidelined and described family conflict about changing responsibilities for care within the family. Authors report developing a 5 day goal-setting training course for yp (based on DAFNE) with follow up from key workers and a half day for parents; a 4 session parent education course on family communication about diabetes for parents; and agreeing to hold a multi-disciplinary meeting before clinic “to agree care priorities” for each patient in order to inform a more consistent approach</p>
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<p>12. Marshall et al 2013 Diabetes (schools) To examine the role of nurses in supporting children in school and EY settings (esp in context of intensification of regimens) Rationale – ‘there is little about how to optimise the quality of ch’s diab care while in school’ p 872</p>	<p>Design Qual Recruitment via RCN, YP diabetes community regional diabetes network, Community Ch’s Nursing networks, professional networks and Diabetes Research Nurses (Scotland) Selection purposive Data collection focus groups which informed follow up indiv phone interviews Data analysis constant comparison Reliability + double coding and discussion - Validity + - .</p>	<p>P/pants 47 acute and community nurses (8 gps, 8 phone interview) all having some patients using intensive therapy Location UK Gender / SES/Ethnicity n/k</p>	<p>Nurses dislike: - Legal and policy framework - ambiguous and inadequate: As there is no legal duty for school staff to administer medicines, unclear about what could be required of schools - DH ‘best practice guidance’ not legally binding, endorse inclusive education but specify parents have primary responsibility for children’s health; nurses felt they could point Heads to necessity of ‘reasonable adjustments’ under Equality Act 2010 but didn’t know how to enforce this as; Ofsted inspections may not be timed when needed. So nurse negotiated arrangements on a case by case basis, dependant on goodwill – and report school co-operation as unpredictable, depending on the head teacher personal views; they said teachers worried about child protection procedures, litigation, health and safety and physical contact – ‘teachers can’t even touch children even if they get a cut knee’ p 873 ‘I can’t be in a room if a child is going to be half undressed’ p873. - How teachers could be scared by hearing from frightened parents at diagnosis; they could lack basic understanding, confusing T1 with T2. - Lack of suitable locations for injecting and testing. - Secondary schools were more problematic, sometimes just seeing their responsibility to provide a place for care, and having different teachers and different places all thru the day could make care complex compared to primary which were easier to deal with cos smaller organisations and children with same teacher in same place all day. - Case load - Some tried to do update visits annually though with increased caseloads this was difficult; some felt school nurses could do more though others felt they hadn’t capacity either. - Lack of evidence Despite guidance from RCN and Diab UK, they perceived a gap in the evid base on how to work with schools to best support children; they felt they learned to negotiate support for CYP by experience only and all this could lead to variations in practice eg even wide variations in amount of time different nurses spent supporting schools. CONC need more evidence about how HCP can influence schools</p>
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<p>13. Lowes et al 2004 Diab To explore parents' experiences of having a child diagnosed with T1D, managed at home, over the first year Home m/ment : discharge 1-3 hr after diagnosis, DSN visit 2x daily first few days (2-3 hrs each), out of hrs phone access diabetes team Rationale – evidence suggests home management safe and cost effective though concerns are expressed about parents coping at time of diagnosis</p>	<p>Design qual longitudinal Recruitment via paed unit of S Wales hospital Selection self selecting from pop of parents of newly diagnosed and clinically well (optimum blood glucose level) children Mar 98- Oct 99 Data collection 3 interviews w/19 parents near diagnosis, 4mths later and a year later; 4 parents single interview at 4 months; 12 parents at 1 year only Data analysis thematic Reliability + Validity + interviewed at home, ch not present, 30-90 mins, iterative schedule, taped, full transcription; analysis discussed with participants and other researchers; divergent case analysis - Interviewer DSN for 70% children in study</p>	<p>Participants 38 parents of ch with T1D median age 38 yrs with children median age 9 Location S Wales Sample size Children's age Gender SES range of occupations from cleaning to journalism, teaching, engineering Ethnicity white English speaking Other information 2 single parent families</p>	<p>Parents alarmed by speed of referral to secondary care after GP diagnosis (authors conclude 'even while awaiting confirmation of diagnosis, they needed info' about the condition and process of diagnosis) All parents wanted to avoid child being hospitalised but 25% initially concerned about going home after diagnosis; most experienced information overload and described prioritising so as to absorb in small chunks, though a small number found the drip feed approach scary – fear of 'what was to come' Parents liked: Accessibility to phone advice- very reassuring - within a week half of parents felt more confident about coping and all were pleased their child had not been hospitalised 3 mothers reported acute distress in the second month, grief at diagnosis. 60% of parents felt home management had helped in introducing diabetes as a manageable condition rather than an illness [this sounds like something framed by the interviewer not participants]; all did their utmost to optimise control 'if we aren't vigilant now we could store up problems for him later' p532; and inexplicable lack of control engendered feelings of confusion and fear. A year later 68% felt diabetes was part of daily life and all but one parents felt they were coping most of the time, tho hypos at night were a big fear, having to plan everything ahead so closely, and one mum reported having given up working outside the home. 39% parents felt it important diabetes was not allowed to become too intrusive in children's lives. A fifth felt home management at diagnosis had helped build their confidence in making the changes to their lives required by the condition. CONC – findings don't support concerns that this model plays down the seriousness of the condition (see for example Scott and Donnelly 2001)</p>
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<p>14. Price et al 2011 Diabetes (trans) To evaluate a transition model and explore elements YP find important. Rationale - Adolescence is a time of 'role confusion where the yp struggles with ideas and feelings about how they might fit into society... need time and space to ... experiment with a variety of behaviours... diabetes may inhibit [this] or conversely lead them to explore risk-taking behaviour involving their diabetes... developmental tasks of adolescence [include] accepting own body, adopting appropriate social roles, developing close peer relationships, preparing for occupational roles [and] intimate relationships, achieving emotional independence from parents, establishing personal values and ethics, striving for social responsibility;' p853</p>	<p>Design qual Recruitment: via young adult clinic Selection yp who transitioned from paed and had had a first apt in young adult clinic within 3 months; Data collection structured interviews (2 YP interviewed again a year later) Data analysis framework Reliability + Validity - explicit theory adolescence - unattributed quotations (no demo of diversity of responses) - no</p>	<p>P' pants 11 YP Location N/K (author based in Tyneside) Sample size Children's age 16-18 yrs Gender/SES/Ethnicity N/K</p>	<p>YP disliked: - A stark change in clinicians' interaction: 'there shouldn't be that much of a difference but it seems as though you're a kid and the next day you're an adult and that was it.. no like in between bit' - Info on drugs and alcohol too late - should be earlier, at 12 years and incremental and preferably written so 'I'll sit and learn it myself' rather than having to discuss - Staff working to a 'set agenda' which could make them consider not attending 'I would rather just not go... [than] listen about me blood sugars and los[ing] weight' p852. They wanted Good relationships with staff (much more important than, for example, the physical environment); above all, having a sense of partnership, collaboration and being recognised as individuals (including having choice about when to move from paed care) - They advised 'get to know the patient on a personal level before you can kind of tailor the advice for them' and 'you're talking to humans... people, and people kind of forget that'. Only one yp was apprehensive, the others didn't have particular memories of how they felt before transfer perhaps reassured by the fact that paed clinicians run the y adult clinic in the same hospital as the paed clinic YP had meetings with clinicians about their impending transition separate from their regular clinic visits (on same day) but experienced these as 'a standard part of their overall healthcare experience' so could have been done in routine appointments. CONC – yp did not identify key elements of the pathway but rather highlighted the quality of their interaction with HCP as central to their experiences. Authors call for prof training, and: 'it is clear that [didactic] interactions that do not take into account a yp's needs or views can be frustrating... from an understanding of where adolescents are in their life stage development it can be argued that taking such an approach becomes more crucial than ever... profs need to understand adol as a life stage with all its biological and psychosocial changes*, as well as communicate effectively with yp on an individual basis'</p>
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	engagement with critiques of developmentalist approaches		
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<p>15. Brooks et al 2013</p> <p>Complex LTC</p> <p>Aim: In light of recent policy to identify and map the model of service in operation and explore user/carer/HCP experiences of it</p> <p>Rationale – exploring how much policy ideals have influenced practice</p>	<p>Design case study</p> <p>Recruitment Trust, postal invite or via Trust support group</p> <p>Selection not explicit but probably families with a child receiving care for complex needs (defined as a long-term condition requiring care from more than one agency DCSF 2008); not sure how staff selected other than they had ‘have sig input into children and families’ care within the study locality’</p> <p>Exclusions Families in Child protection or complaints proceedings</p> <p>Data collection local/national doc and policy review, in-depth qual interviews and focus groups</p> <p>Data analysis in depth thematic</p> <p>Reliability + double coding -</p> <p>Validity + mainly home family interviews, except support grp who chose focus grp approach, profs at place of work, pilots, taped, full transcription -</p>	<p>Participants 14 parents (inc 1 father); 2 girls; 18 staff (interviews) plus ‘a wide range of individuals eg community paed, nurses, therapists, and teachers’ (data collection not clear)</p> <p>Location large UK NHS Trust</p> <p>Children’s age 6 and 10</p> <p>SES n/k</p> <p>Ethnicity (reports lack of ethnic diversity)</p>	<p>Apart from needing respite care, parents main concern was communication –</p> <p>a) a lack of coordination across services sometimes resulting in conflicting advice from different profs, or an ‘information gap’ between hospitals and community services eg community paed not having details of acute admission and discharge – and fast-tracked admission to A&E for this group was not working either, took as much time as usual admission cos of A&E not having the right file. Participants highlighted the need for a designated lead, or case manager</p> <p>b) parents felt they didn’t have info they needed about child’s condition nor about services to support them; felt they had to learn a particular style of communication to be heard by professionals: assertive and demanding as opposed to ‘a supportive dialogue’. Profs felt they wanted to support parents learning how to develop these skills though parents felt they did not respect their position as ‘expert parents’, their knowledge and expertise gained over the years, and they were not sufficiently involved in decision-making esp when changes were made to the care regime, for instance in hospital.</p> <p>CONC, as Sloper et al 2003 found, that multi-agency planning is needed to ensure co-ordination of services, assessments and appointments and there should a single key worker to liaise with and assist the family consistently.</p>
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<p>16. Carter et al 2007</p> <p>Complex needs</p> <p>To explore appreciatively examples of best multi-agency working to determine what works well, why and what best practice in future should be</p> <p>Rationale – policy-practice gap between ‘regulatory ideal’ of ‘partnership/sea mless care’ and evidence services are not experienced that way</p>	<p>Design Appreciative enquiry</p> <p>Recruitment not clear, though mentions snowballing staff</p> <p>Selection Purposive (families diff geog areas; staff as many different agencies)</p> <p>Data collection appreciative interviews; nominal group workshops based on statements from interviews, consensus workshops</p> <p>Data analysis interviews thematically;</p> <p>Reliability + -</p> <p>Validity + taped interviews, full transcription -</p>	<p>Participants 20 mothers, 7 fathers; 1 child; 41 professionals</p> <p>Location Cumbria and Lancashire</p> <p>SES /Ethnicity n/k</p>	<p>Participants felt things work well when...</p> <ol style="list-style-type: none"> 1. The child and family are central to information and decision making 2. Everyone involved in the child’s care works closely together and shares a common vision to ensure that, from the start, the child’s needs are met, prioritized and planned for holistically 3. Everyone involved in the child’s care understands and respects each other’s role, expertise and the contribution that they can each make and then works (engages) appropriately with the family 4. Everyone involved in the child’s care and the systems they work within are accessible, available, flexible and responsive 5. Communication is timely, accessible, shared and appropriate 6. The family has the time to be a family and their need for psychological and emotional space is respected 7. People involved in working with children with complex needs have the support and freedom to be innovative and to work collaboratively across and within organizations 8. Parents have the opportunity to be linked with other parents in similar circumstances to facilitate mutual support and sharing of experiences 9. Information collected about the child is streamlined and centrally accessible to reduce the family’s burden of repeating information about their child/children 10. Parents are given choice, throughout the child’s life-journey, to have a person who could act as a coordinator of care and who has in-depth knowledge of them and their child
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17. Cejer	Design Review	Papers 8	In PICU , parents disliked
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<p>2007 Ventilated children</p> <p>To identify the present state of knowledge about these needs and experiences.</p> <p>Rationale - HCP increasingly caring for long term ventilated (LTV) children and their families, planning and delivering complex multi-disc healthcare packages. To do this effectively HCP must understand the needs and experiences of children and families.</p>	<p>Sources: Allied Complementary Medicine, BNI, RCN Journals, CINAHL, hand searching journals</p> <p>Selection: studies 15 yrs old or more recent in English that explored experiences of LTV children and their families</p> <p>Data analysis thematic</p> <p>Reliability</p> <p>+ - Validity</p> <p>+ -</p>	<p>small scale qual studies</p> <p>Location 6 UK, 2 USA</p> <p>Children's age</p> <p>/Gender</p> <p>/SES/</p> <p>Ethnicity N/K</p>	<ul style="list-style-type: none"> • Delays in discharge while funding/arrangements made for provision at home eg purchase of equipment, new housing if necessary, recruitment and training of carers (authors say lack of 'central agreement for funding LTV packages mean PCTs deal with each case individually – changed since then?) • Discharge badly co-ordinated across agencies, managed by nurses lacking time and/or training to do this effectively, feeling meetings have taken place without their inclusion • Feeling unwanted while awaiting discharge as aware child potentially blocking bed needed for acutely ill child and that prolonged stays are damaging for their child psychologically and negatively affects behaviour • Long travel btw unit and home where the rest of the family are living and having to relate to their child under the constant gaze of HCP <p>And if alert YP distressed by</p> <ul style="list-style-type: none"> • witnessing trauma of distressed relatives • seeing other children leave the unit • restrictions and routines of the unit/loss of control and loss of 'normal' activities like schooling and going out to see friends which can only be done with lots of planning <p>At home parents and yp experienced considerable stress and financial burden. For parents struggled with</p> <ul style="list-style-type: none"> • having to plan with great precision to ensure smooth running of household as well as strict adherence to routines to avoid hospital admission and all the disruption associated - and not being able to have holidays because of equipment/ amount of planning needed • uncertainty of living with a child with life limiting condition and constant observation of child to detect deterioration • having carers constantly present (though some were coping without carers and negative impact on their view of themselves as parents because of having to carry out painful/distressing nursing procedures <p>YP (views reported in 2 studies only) struggled with</p> <ul style="list-style-type: none"> • lack of freedom to do 'normal' activities such as going out or seeing friends and lack of control over their lives leading to behavioural/psychological problems (especially for 2 boys who lived in a residential home rather than with their families for whom lack of privacy from staff was a particular concern) <p>Parents and YP want</p> <ul style="list-style-type: none"> • YP to live at home, integrated into society as much as possible • Parents – it was usually mothers who was the primary carer – wanted time with their child doing 'normal' parenting activities, perceived differently from nursing activities such as suctioning <p>CONC – LTV children spend an extra 9 months in hospital awaiting discharge once medically stable: services need to provide more co-ordinated approach to planning and delivering care eg 2005 LTV Care pathway details best practice</p>
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<p>18. Maddox and Pontin 2013 L/T ventilated children</p> <p>To describe carers experiences of caring for CYP and families in their own homes</p> <p>Rationale – anecdotal exp of 'support issues' and 'carer-parent</p>	<p>Design qualitative abductive design</p> <p>Recruitment 'service providers'</p> <p>Selection purposive to identify carers with experiences of caring for ventilated children day and night in children's own homes and end of life care</p> <p>Data collection diaries, semi-structured interviews, researcher reflexive notes</p> <p>Data analysis 'hermeneutic cycle of data construction, analysis and critique'</p> <p>Reliability + use of researcher reflexive notes; data management software used for diary data</p>	<p>P'pants 3 paid carers</p> <p>Location W</p> <p>England</p> <p>Gender women</p> <p>SES n/k</p> <p>Ethnicity n/k</p>	<p>Paid carers worried about</p> <ol style="list-style-type: none"> a) caring for children with parents there as differences in their way of doing things could be interpreted as doing something wrong - any challenges from parents were felt to be an 'assault on their personal integrity' / ability though equally they said they defer to parents as experts if they are unclear what to do b) maintaining boundaries eg being expected to administer medicines, which legally they can't, not even calpol, do housework, mind siblings, advice on school behaviour or act as counsellor c) their training was rushed, uneven/patchy d) feeling sad when children die (also happy times, respect and hospitality from parents too though) e) lack of support mechanisms for 'minor' incidents esp as previously available phone support from managers was withdrawn – lack of supervision at night - carers liked support sessions intro'd as part of team meetings <p>CONC inc a suggestion to include parents in carers training in order to build their confidence in working with them; and for access to registered nursing support by phone out of hours.</p>
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relationship' strain	- Validity + - sample size small without esp thick description		
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19. Noyes 2006 Ventilator dependent CYP To describe the experiences of ventilator dependent CYP and their parents, and meanings concerning the children's health and quality of life. Rationale – 'ascertaining children's perspectives is important to inform the emerging evidence base'	Design phenomenology Recruitment via 11 UK hospitals Selection purposive – parents (by gender); children: by gender, time using ventilator, age, ethnicity, living at home/hospital/LAC Data collection interview with topic guide, some draw/play techniques or computers with children Data analysis Framework Reliability + data management software; joint analysis and discussion w/other researchers - Validity + taped recorded or note-taking where this was refused (n=3); audit trail of researcher decision-making; prolonged engagement in the field; play based approaches -	Participants 35 ventilator-dependent children, and 50 mothers and 17 fathers of 53 v/d children Location UK Children's age 6-18 Gender NK as gender totals include some children who weren't interviewed (parents were) SES Ethnicity 12 'ethnic minority' parents or children Other information 3 LAC, most children had communication difficulties such as speech affected by ventilator, 7 needed carer to help communicate Exclusions 'children under 6 years... because the main purpose of the study was to ascertain children's own perceptions',	Home healthcare services were not designed to bring about the desired social outcomes that children identified eg social inclusion by being able to get out and about and take holidays, and have a good social life; and children seemed most disadvantaged when parents did not have the resources (such as transport) to compensate for this in ways that could support their child's social inclusion. CONC Flexible, high quality child-focused homecare is likely to improve children's outcomes.
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20. Shilling et al 2012 Disabled children To integrate qual studies on the experiences of disabled children as inpatients in hospitals Rationale – rights and policy framework round listening and respecting children's views	Design structured review and synthesis Recruitment/searching: Medline, Embase, PsycINFO, BNI, Health Management Info Consortium, Cochrane library, DARE, CENTRAL, Methods studies (3), Technology Assessments (3) Economic Evaluations (3), CINAHL, SSCI Selection: qual studies focussing on experiences of CYP less than 18 yrs with chronic health condition or neurodisability during inpatient stay Exclusions: intensive care and outpatient experiences Data analysis : thematic Reliability + double coding - Validity + -	P'pants 8 papers on exps of CYP and parents and staff Location 5 UK, 2 Ireland, 1 Canada Children's age 3-17 Gender n/k SES n/k Ethnicity n/k	Parents disliked - nurses' routinely underestimating children's levels of understanding - lack of info on CYP condition and treatment - unclear division of care with staff, since nurses tendency to defer to them as experts in their child's care could shake their confidence in the clinical team. CYP were frightened when - procedures were not explained or when children were excluded from decisions - use of medical jargon could be a problem - could find ward routines restrictive eg waking/sleeping times also concerns about missing school work and friends and family Nurses found it difficult - to judge children's capacity for involvement in decisions - had no framework for doing this - found parents wanting to 'protect' children could lead to their being excluded from discussions - especially difficult to involve children with high levels of knowledge about their condition. Children described experiences as positive when - procedures were explained to them including potential pain, tho fun and jokes to add levity were appreciated. - they were asked about their views and involved in decisions - described this as reducing anxiety and making them feel more respected - there was camaraderie amongst other 'regular' inpatients and - positive, friendly, honest interaction with staff (central to their views on care. CONC open discussion of roles and responsibilities during the inpatient stay may clarify boundaries btw staff/parents/child's care. CYP experiences may not be 'optimal' and improving staff communication skills is important to address this.
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21. Santer et al 2012 Eczema To explore views/exp of	Design qual interview study Recruitment via primary care invites, 10% agreed	Participants 31 carers of children 5yr or younger w eczema from 28 families (21	Parents disliked - feeling unsupported, frustrated with both medical care (14 in primary, 5 dermatology nurse, 9 dermatology/allergy clinic) and treatments. - feeling their child's suffering was not 'taken seriously', - experienced messages about a 'trial and error' prescribing approach and
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<p>carers of eczema + its m/ment</p> <p>Rationale is to explore parental views of treatment as poor adherence is a 'major cause of treatment failure' - sometimes because of poor understanding of topical preparations. 'A first step in addressing adherence is to understand beliefs about condition/care.</p>	<p>Selection parents of ch with eczema under 5 years</p> <p>Data collection qual interviews mainly at home</p> <p>Data analysis constant comparative</p> <p>Reliability + used software to manage data; dbl coded and discussed;</p> <p>-</p> <p>Validity + taped, interviews at home; full transcription; neg case analysis;</p> <p>-</p>	<p>mothers, 1 father, 3 both)</p> <p>Location Hampshire + Dorset</p> <p>Sample size</p> <p>Children's age</p> <p>Gender</p> <p>SES recruitment from 'varying sociodemographic areas'; included 8 professionals and 8 admin/retail</p> <p>Ethnicity 25 white brit; 3 blk/Asian brit; 1 mixed heritage brit; 2 white non-british</p>	<p>assurance that their child would 'grow out of it' as a further 'fobbing off', or dismissal (a few were also confused about the information they'd been given on topical corticosteroids).</p> <p>- frustrated with doctors focus on 'control' (national guidelines) whereas they wanted cure, eg through allergy testing.</p> <p>- felt judged by their HCP as a parent, and felt upset and angry about this. 'They're looking at it and they're like 'IT's very dry'. IT's a stupid question 'Are you moisturising?' Well yes I am. Why would I want my child to go through that... they are quick to criticise when they are not really helping me'</p> <p>- ambivalent about eczema treatments, mainly topical corticosteroids but also emollients – 'I would prefer not to guinea pig them and 'let's see if this cream works' p 263</p> <p>- not understanding advice or receiving conflicting advice from different healthcare providers</p> <p>Parents interested in</p> <p>- dietary exclusions as a potential cure - many were trying out changes without discussion with a HCP, tho often felt unsure about these – tho perceived healthcare professionals as uninterested in this.</p> <p>CONC – 'experiences of conflicting or not understanding advice may have delayed the process of gaining control... for some' p265</p>
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<p>22. Lewis et al 2010</p> <p>Epilepsy</p> <p>To id what is effective in delivering information to YP 13-19 years with epilepsy and their parents, describe their experiences of info exchange and to id factors influencing positive and negative healthcare communication</p> <p>Rationale – 'current philosophies in selfcare.. focus on yp becoming experts in their own care by the time they transition to adult services. Adults whose epilepsy began in c/hood have id/d important gaps in communication during their early years.' P2</p>	<p>Design Systematic mixed methods review</p> <p>Recruitment/sources DARE, ASSIA, Medline, Cinahl, Cochrane Epilepsy Specialised Register and Cochrane Central register of controlled trials; handsearches of key journals; 10 authors contacted for additional information – 'some' responded</p> <p>Selection studies of the knowledge, use of information, info needs and experiences of yp 13-19 with epilepsy and their parents in healthcare published in English or translations available</p> <p>Excluded studies of age group wider than 13-19 where data from this age group could not be extracted separately</p> <p>Data collection</p> <p>Data analysis adapted guidance from Thomas and Harden 2008</p> <p>Reliability + used Ley's cognitive hypothesis model of communication to inform interpretation of findings; used software data management</p> <p>-</p> <p>Validity + -</p>	<p>Participants</p> <p>10 qual, 5 intervention studies, 4 quant non-intervention,</p> <p>Location: Country of included studies not reported</p>	<p>What YP wanted</p> <p>13-15yrs yp wanted info on about practicalities of living w/epil 'here and now' eg not about causes</p> <p>Older yp wanted to know about implications for future education, employment, marriage, children</p> <p>All wanted to know if being tired, sleeping/concentration/memory problems were related to epilepsy or medicines</p> <p>They wanted individualised structured education on demand thru out their teenage years</p> <p>Somewhere quiet to talk with a prof with the right communication skills</p> <p>Barriers to YP getting this</p> <p>HCP focus on medical information (including at diagnosis) rather than practicalities of living with epilepsy: yp thought they are only interested in medical management</p> <p>Felt excluded from discussions in clinic (directed at parent, and jargon difficult to follow so they stopped listening, adopted a passive role</p> <p>YP felt having to repeat the same information to high turn over of different health profs depletes sense of partnership too</p> <p>Doctors' high status and limited time in consultations, seeing different staff each time made discussing sensitive issues difficult</p> <p>YP feared asking questions feeling they would be judged eg not following the regimen, or assumed to be involved "risky" behaviours such as drinking or having sex.</p> <p>YP felt HCP knew they had 'emotional issues' but 'pretended not to be aware of it to avoid discussion as they did not know how to deal with it' (NB cross ref with paper on doctors feeling they reassure via clinical, instrumental, not emotional, skills)</p> <p>Parents' presence could be inhibitive (tho at other times, supportive)</p> <p>What parents wanted</p> <p>'adequate' info from HCP (so they didn't have to go to the internet) including info on side effects, on prognosis and practical advice inc about their children's behaviour and managing problems at school</p> <p>a contact point when their child has a seizure</p> <p>(Authors: 'YP made improbable links and tried to make sense of the epilepsy through personal experiences rather than actual facts about the condition' p12). '</p> <p>CONC: Information exchange and self-care round transition is not working well which 'explains why profs in adult care report yp entering adulthood ill equipped and lacking in knowledge and self-care expertise... there are few effective interventions that healthcare professionals can draw on p16</p>
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<p>23. Hummelinck et al 2006</p> <p>Chronic illness generally</p> <p>To explore the complexity of parents' information needs and how current information provision is evaluated.</p> <p>Rationale is gap between policy/rights agenda emphasis on providing comprehensive information and patient dissatisfaction with this ('despite widespread dissemination of info materials')</p>	<p>Design qual</p> <p>Recruitment 45 invitations via paed dept of district general hospital</p> <p>Selection convenience from parents living with ch 0-16 yrs with chronic condition and at least 1 drug administered daily for minimum of 1 week</p> <p>Data collection semi structured interviews</p> <p>Data analysis thematic</p> <p>Reliability</p> <p>+ - Validity + taped (or full notes) and full transcription - not clear where interview or who conducted</p>	<p>Participants 27 parents of 20 families</p> <p>Location W Midlands</p> <p>Sample size</p> <p>Children's age median 6-10yrs</p> <p>Gender 12 boys 9 girls</p> <p>SES/ Ethnicity n/k</p> <p>Other information median time since diagnosis 2-4 years; conditions including asthma, diabetes, CF, epilepsy (including with special needs),eczema, cancers</p>	<p>Parents disliked</p> <ul style="list-style-type: none"> -having to absorb lot of info at diagnosis and many felt overloaded (especially where condition managed across multi-disciplinary teams eg CF) - feeling confused by jargon or frightened because they could not find answers to their anxieties. - Conditions managed in primary care (eg asthma) tended to be characterised by concerns about lack of information. - not knowing how to frame questions as they didn't know what to ask, what they needed to know until they were in an unfamiliar or critical situation - feeling most professional communication and info provision inadequate – some described actively seeking out information but one coping strategy was actively resisting information for fear of its negative impact. <p>In retrospect, parents said they wanted to know</p> <ul style="list-style-type: none"> - Explanation for illness - Understand management (treatment, mechanism of drug action, possible side effects) and possible outcomes - And practicalities of this in terms of daily care psychological and medical eg medicines supply issues, insurance cover, improving acceptability to children, available support systems/reliable info sources - Prognosis and potential complications – to prepare for these <p>Later information needs were shaped by parents feelings of confidence in dealing with the condition and administering treatment, possibly linked to length of time since diagnosis and stage of child's illness – so confidence displaced need for further formal education.</p> <p>CONC – 'individual info needs varied... [also] resisting or avoiding information could be used as a positive coping strategy in some situations' (if parents felt overwhelmed). Parents felt information 'inadequately tailored to their individual current or anticipated needs' p233</p>
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<p>24. Kirk et al 2012</p> <p>Self care support</p> <p>To determine CYP/carers/HCP perceptions of the effectiveness of different models of self care support and id factors that support/inhibit self care at individual and organisational level; and explore how models integrate with self care support provided by other organisations NB 'the self in this context is a combination of child and adult carers' p1975</p> <p>Rationale - 'self-care support... in the context of a LTC [is] largely associated with particular interventions [rather than routine care] such as education or skills training [so] constructed largely in terms of the individual patient rather than structural constraints' p1975 Cites evidence of yp/parents valuing 'group based self-care for the opportunity they provide to interact with others' and that 'e-health methods' of support have also been found useable and acceptable. But 'flexibility in provision is needed to</p>	<p>Design case studies of 6 different models of self-care support</p> <p>Recruitment 70 self care support projects identified in previous research</p> <p>Selection purposive of projects to reflect diff ways of providing support, condition specific models and general; purposive to maximise variation of children's ages, support by different types of workers (voluntary, HCP) and to try include those who had dropped out.</p> <p>Data collection semi structured phone interviews (except where requested otherwise), observation of self care support activities; relevant documents reviewed</p> <p>Data analysis Framework</p> <p>Reliability</p> <p>+</p>	<p>P'pants 26 YP, 31 carers, 36 self care support providers from projects such as support groups (inc online and lay led), residential camps, statutory secondary health care – diabetes team)</p> <p>Location UK</p> <p>Children's age / Gender /</p>	<p>Organisational inhibitors of self care or access to self care support (why do authors conflate these?)</p> <ul style="list-style-type: none"> - Parents identified primary schools - esp for ch with asthma not allowed to keep their inhalers with them (undermined what they'd been encouraged to do at asthma camp) or when schools did not action plans agreed for management. - YP identified schools as exacerbating their feelings of difference from peers - NHS routine referral to support projects generally reported poor (except to NHS led ones) <p>Individual level facilitators of selfcare support or access to self care projects</p> <ul style="list-style-type: none"> - YP said mothers played central role in encouraging them to attend self care projects and mothers/yp said yp would have to feel 'ready' to attend - Both reported enjoying a 'safe place where feeling and experiences could be expressed' (at odds with other evidence) - Parents wanted to learn about the condition and management strategies and promote children's independence and described feeling that they'd got this - YP described learning how to manage feelings, improve communication with HCP and teachers,
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<p>enable individuals to access a range of different types of support from both formal and informal self-care resources as well as support that takes account of social-economic and cultural contexts' p1975. Interventions need to be directed at HCP and systems as well as patients evidence these can improve CYP health status and reduce health service use.</p>	<p>- Validity + - Authors were unsuccessful in recruiting any project 'drop-outs'; - little report of any differences/tension in experiences across diff groups eg YP / carers</p>	<p>SES / Ethnicity N/K</p>	<p>and self-confidence and they liked when activities were enjoyable CONC – 'promoting self-care support or an individual child/family basis by HCP and maintaining personal involvement appears to be important factors in encouraging yp to access self-care support' p1985.</p>
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<p>25. Pontin and Lewis 2008a₂ Community children's nursing (CCNs) To identify CCNs perceptions of their workload in a system that uses a 'family nursing model' Rationale – the dependency scoring case allocation method in CCN is not working because all children [with life-limiting, life threatening and chronic conditions in the community] on a given CCN caseload will score as highly dependent... so CCNs cannot use the system to differentiate between those children in order to manage their caseload to meet client need' Authors say also there is 'insufficient robust data to discriminate between ongoing workload trends and minor self-limiting events' p27)</p>	<p>Design Action research Recruitment CCN service Selection: not clear though all CCNs may have participated in develop/piloting templates of high/med/low nursing 'input'; purposive sampling for interview on location, length of experience Data collection in-depth interviews; doc analysis of caseload data, fieldnotes, analytical memos used to develop interview schedules Data analysis thematic Reliability + data management software - 'family nursing model' not described (tho in other paper this is linked to family systems theory and continuity of care Validity + taped and transcribed; iterative schedule and analysis - interviewed 'at the university'; relation between aim/finding/conc rather loose and tensions between explicit organisational ethos and nurses' views not flagged.</p>	<p>P'pants 6 CCN Location West of England Gender /SES/ Ethnicity NK</p>	<p>CCNs reported the development of both formal and informal (written and oral) protocols to manage their workload including: - an aim to support families to have a 'usual' family life - anticipating issues early to avoid negative consequences - getting to know families well (not a straightforward 'linear' process) before they could advocate for them across other services – discouraging families from being 'too dependent' on nursing care or one CCN In this paper authors say '[CCNs] recognise their actions could engender service dependency' p30 Perhaps unsurprisingly families are reported reluctant to 'ring for help regardless of the situation' p31. CCNs valued establishing strong relationships with families as this helped if/when children were dying They tried to ensure they always had a clear purpose for visits 'they monitor their actions and justify them... to themselves and the 'unseen other' through their records'p31 However, 'despite CCN attempts to ensure purposeful visits.. clients have the ability to shift the initial premise of the visit to meet their own needs... CCNs construct daily plans of action [but] the smooth sequencing of these plans is a risk if clients change the visit purpose [so] CCNs prioritise/revise them on a visit-by-visit basis' p32 CONC - Authors refer several times to nurses concerns that their work in the home is 'invisible' to commissioners (see Byrne 2003), and their need for this to be made 'extant'</p>
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<p>26. Pontin and Lewis 2008b² CCN To explore factors that affect CCN perceptions of their workload; how they develop and maintain continuity of care and carer; how can this be used to devp a system for caseload management Rationale – the nursing service has 'an explicit rationale to maintaining continuity of care and carer which is challenged by the context of delivery'; nurses in a particular CCN service wanted to find ways to ensure efficiency and equity of service delivery and wanted</p>	<p>Design Qual action research Recruitment CCN service across several PCTs Selection: purposive sampling for interview on location, length of experience Data collection in-depth interviews; doc analysis of caseload data, fieldnotes, analytical memos used to develop interview schedules Data analysis thematic Reliability + - Validity + taped and transcribed; - interviewed 'at the</p>	<p>Participants 6 CCN Location Urban and rural Other information CCN serving 'diverse population'</p>	<p>CCNs reported meeting family needs thru interagency working to accommodate developments eg when mother becomes pregnant and unable to lift CNNs share out clients including by geographical location, or who has known them the longest. Meaningful working relationships with families are 'highly rewarding' but can be stressful, not least because of the 'amount of information and local knowledge' CNN must 'take on' to support families. Having responsibility for named clients across the job share facilitates information exchange, Junior colleagues were allocated some named clients too tho senior nurses retained overall responsibility for them. CONC – 'findings show how nurses maintain continuity of care in a particular model of</p>
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<p>'caseload management information to use as part of a strategic approach to negotiating additional resources with commissioners to meet changing demand' p1201.</p>	<p>university'; relation between aim/finding/conc rather loose; uses term 'responsibility relationship' but doesn't explain</p>		<p>service delivery'</p>
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<p>27. Shepherd 2014</p> <p>YP with LTC</p> <p>To highlight the emotional impact of being in the hospital for young people, and to explore the impact of the care by younger student nurses on promoting a sense of "normalcy" for them. Rationale- students nurses may be especially suited to 'engage in caring interactions with yp in hospital' because of 'their age and similar stage of devp [and] they are experiencing a similar 'lifeworld' . Reviews show 'one of the main concerns for yp is striving for normalcy and the need for HCP to focus on their wellness not their illness' p1055</p>	<p>Design Heideggerian phenomenology Recruitment nursing students via via author institution; not clear re YP, pos outpatients? Selection: students under 20 yrs at start of 'programme' who had 'experienced the phenomenon' –caring for a yp in hosp? YP over 12 yrs with exp of at least 3 hosp admissions and using trust outpatients Data collection unstructured interviews Data analysis interpretative phenomenology Reliability + used data management software - No discussion of conceptual framework, 'lifeworld' is central concept but not clarified Validity + - Limitations not discussed, nor impact of gender, generalisabilty may be issue - little known about participants apart from age/gender</p>	<p>Participants 11 17-18 yr old student nurses, including one young man; 9 13-18 yrs YP in hospital with chronic condition (3 boys) Location not stated but author is at Greenwich university SES /Ethnicity n/k</p>	<p>YP wanted care that relieved their boredom, made them forget their illness for a while and provides a sense of normalcy eg '[she] knows the same places where everyone goes' p1037 CONC 'in order for the care giving to be supportive and therapeutic the carer must be tuned into the person's ontological concerns... because the students are experiencing a similar lifeworld... they are seen as being able to engage in ontic care giving' p1039</p>
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<p>28. Swallow et al 2013</p> <p>Chronic kidney disease (CKD)</p> <p>Explore social interaction between multidisc teams (MDT) and parents, how they negotiate care roles by a) developing a descriptive profile of MDT and their parent-education activities; b) explore profs accts of strategies during these activities; c) get a focused understanding of prof/parent interactions as parents embark on new interventions at home Rationale – increased prevalence of CKD, parent-led care at home is deemed best practice but non-maintenance of regimen or failure ot detect complications has emotional, pshycial and financial costs for families (financial/policy implications for services). There is little evidence on factors important in parent-prof interactions when parents are mastering the skill to incorporate care into day to day parenting roles.. studying the way parents and profs communicate will help profs determine how to individualise parent support from early in the trajectory. Current evidence suggests 'unresolved tensions' and 'lack of negotiation around healthcare decisions' Conceptual framewk from 'Communities of practice and activity theory': in which learning is by doing, individuals must work out how to engage with one another (eg</p>	<p>Design multi-method Recruitment via kidney units Selection MDT members identified by unit PI; self-selected to interview; case studies purposively sampled by CYP age, sex, ethnicity, type of care, and profs involved in this care identified via snowballing Data collection (initial survey); then qual grp (indiv interviews if staff couldn't make grp); then 6 month ethnographic case studies involving: - observation prof/parent interactions at home sharing care - individual interviews with HCP and parents - case note reviews Data analysis Framework Reliability + dbl coding; - Validity + researchers repeatedly explicit not 'judging' or 'testing' HCP or parents' practice; 'incorporated reflexivity into data management process by regularly considering whether analysis might have been compromised in favour of</p>	<p>Participants 115 prof interviews (7 indiv interviews) with psychologists, dieticians, doctors, nurses, play spec, pharmacists, therapists, soc workers; 6 observational case studies involving 6 children, 6 mothers, 4 fathers, 2 grandparents, 28 prof, 86 observations, 41 interviews, selected case note and documentary reviews Location 12 british children's kidney units CYP age 5 mths-15 yrs Gender CYP: 2 boys SES: N/K Ethnicity CYP 1 Sth Asian, 5 White Brit Other info: parents were learning how to insert NG tubes, gastrostomy feeds, home dialysis, monitoring diet/fluids, clinical observations,</p>	<p>HCP say they negotiate care roles by - using tacit knowledge to gauge parents learning needs, how to pitch communication ('it's intuition')p7 - set goals for optimum management with needs and preferences of children and parents - and used a 'staged' approach to conveying specialist clinical knowledge - check out and refine info with other member of the MDT inc common assessments of parents levels of understanding - use common tools such as words, metaphors, diagrams, stories, routines, dolls or concepts to explain to parents 'How the kidney does a lot of work and is made of a whole lot of little factories' Doctor p8 - as part of this draw on parents expert knowledge of and relationship with their child CONC – did not observe any tensions; profs may find it hard to make explicit tacit knowledge about how they assess parents'</p>
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who knows what); negotiate a set of shared tasks; from which will emerge a shared repertoire of tools and routines drawing on tacit as well as explicit knowledge	our own preconceived ideas' -	observing subtle clinical changes, acting on and communicating these to HCP	learning needs; negotiation of roles is a two-way process between profs and parents.
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<p>29. Smith, Taylor, Newbould and Keady 2008</p> <p>Medicines in school</p> <p>To examine the experiences and concerns of YP with chronic illness and their parents in managing medicines in school</p> <p>Rationale – ‘CYP with chronic illness should be able to lead as normal lives as possible (DH 2004)’ but there is evidence that despite the ‘Supporting Pupils with Medical Needs’ (1996) guidance and from the NSF, CYP experience difficulties in maintaining regimens and administering medicines at school.</p>	<p>Design not explicit</p> <p>Recruitment respiratory, endocrine, rheumatology and gastro, and adolescent outpatients in major London teaching hospital</p> <p>Selection 5-19 years in f/t education (postal invite)</p> <p>Data collection face to face semi structured interviews (at clinic)</p> <p>Data analysis constant comparative</p> <p>Reliability + - Validity + taped and verbatim transcription</p> <p>-</p>	<p>Participants 27 YP and parents (n=n/k)</p> <p>Location London</p> <p>Children’s age 6-19 yrs</p> <p>Gender 17 girls</p> <p>SES ‘small number’ attending private schools</p> <p>Ethnicity N/K tho authors report clinics serve diverse populations</p> <p>Other information 11 adol medicine, 7 endocrine, 5 rheumatology, 3 respiratory, 1 gastroenterology; 19 YP had regular dosing and ‘prn’ (as needed)</p>	<p>YP and parents described problems with</p> <ul style="list-style-type: none"> - No private place for administration - No advice available when feeling unwell - No reminders to take medicines for yp - No help with administration <p>Staff having poor knowledge and awareness of yp needs</p> <p>They wanted better support, esp with prn medicines eg analgesics including:</p> <ul style="list-style-type: none"> - access to medicine as needed (and promptly), without drawing attention to yourself - somewhere private to administer (half of yp wanted to keep condition secret) - if necessary a designated first aider to oversee, inc on trips (or remind when needed) - individual teachers assistance eg to catch u p with work after hospital admission - flexible application of protocols (eg ‘he let me look after my medicine’) <p>CONC –</p> <p>Schools should address separately the needs of yp with prn medicines from those with routine regimen; individually assess yp’s needs (some need privacy others don’t); make sure staff training is in place to address the marked variability in support YP experienced</p> <p>Prescribers should use medicines with one or two doses daily where pos</p>
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<p>30. Soanes and Timmins 2004</p> <p>Transition LTC</p> <p>To examine the attitudes and needs of adol with chronic illness transferring to adult care?</p> <p>Rationale is to examine whether existing organisational structures militate against successful transition.</p>	<p>Design qualitative</p> <p>Recruitment: via large, teaching hospital youth club</p> <p>Selection: Purposive by age (14-18) likelihood of having personal experience of transition, and long-term illness</p> <p>Data collection half hour semi-struct interviews in youth club</p> <p>Data analysis ‘coded for content... then codes refined’</p> <p>Reliability +</p> <p>-</p> <p>Validity + full transcription, taped, flexible schedule</p> <p>- authors acknowledge generalizability limited; NB bias of recruitment via hosp youth club.</p>	<p>Participants 7 YP with LTC</p> <p>Location N/K</p> <p>Children’s age 14-17 yrs</p> <p>Gender 2 girls</p> <p>SES / Ethnicity n/k</p> <p>Other information 4 with diabetes, 2 chronic renal failure and 1 cancer</p>	<p>YP want</p> <ul style="list-style-type: none"> - informal approaches which make them feel comfortable ‘I like knowing everyone... be able to chat with them. The hospital is a sort of second home’ p 104 <p>Some felt paed services attractive for their informality whereas others found them condescending and no longer appropriate to their needs</p> <ul style="list-style-type: none"> - transition to be gradual with lots of preparation ‘a year or two in advance’ when they are ready, not coerced ie flexible, individualised process and supported by nurses and youth workers - didn’t want family involved for long <p>YP felt info on drugs and alcohol was poor in paed services</p> <p>CONC – services must review the types of info available, consider a ‘buddy’ system, evaluate the use of an informal day or residential weekend to facilitate transition, use factors other than age as indicators of readiness to transfer.</p>
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<p>31. Taylor, Gibson, Franck 2008</p> <p>Living with LTC during</p>	<p>Design SR</p> <p>Sources: Medine, Cinahl, PubMED, PsychINFO</p>	<p>20 studies,</p> <p>Location N/K; CYP age: 10-19</p> <p>Gender /SES/</p>	<p>RE care and treatment, YP disliked</p> <ul style="list-style-type: none"> - clash between treatment and priorities in wider life, felt especially in middle adol when authors feel they are taking more responsibility from parents, though as they got older are reported to take control by developing their own routine - lack of support in schools from staff who imposed unnecessary restrictions, didn’t know enough about their condition and made it hard for yp to maintain their valued sense of
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<p>adolescence To identify, describe and critique lit on 'the adolescent lived experience of chronic illness Rationale – living with illness can 'disrupt adolescent development' p3085 but little is known about how YP perceive this</p>	<p>Selection: qual studies with yp 10-19 yrs in English on experiences of living with illness Data analysis thematic Reliability + explicit theory of adolescence - Validity +studies were QA'd - no engagement with critiques of developmental psychology</p>	<p>Ethnicity N/K Other info Cancer, renal, diab, CF, IBD, L/T ventilate, SCD, Disability, Asthma, Epilepsy, Depression, Cerebral palsy, Treacher Collins</p>	<p>sameness with peers - only in 3 studies did YP make reference to the care team: 'felt devalued if they felt judged' - not feeling respected would make them feel like stopping treatment YP liked - feeling understood, supported and respected by their care team - needed to know about their illness CONC – authors suggest implications for practice as follows: - the importance to yp of developing and maintaining friendships: encourage friends to visit during hospitalisation; 'ensuring early socialisation experiences are optimised' - Importance of family: 'teaching parents coping skills early after diagnosis'; 'teaching parents ways of coping with a teenager' - Attitude to treatment: ensure info about the illness is available in a developmentally appropriate form - Experiences of school: ensuring liaison during periods of hospitalisation; educating teachers about the condition and importance of promoting normality - Reln with HCP: Involve yp in decision-making and engage yp in discussion rather than their parents</p>
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<p>32. Hutchinson, Hall 2007 Rheumatology service To understand young women's experiences of learning about their illness and preferred learning options - to inform a decision about whether the expert patient programme would be a useful 'educational tool' – later: 'to determine the knowledge of yp ... regarding their... illness' p522 Rationale – Authors explain use of new drugs with side effects and how 'education' is needed to 'optimise concordance' 'To facilitate empowered understanding... nurses must first understand the care situation as viewed by those most closely involved' p522 especially as 'imparting knowledge to yp is challenging as they may rely on others to take responsibility for knowledge about their illness... this study arose from recognition of this challenge within one CYP rheumatology unit</p>	<p>Design Multiple case study Recruitment yp's rheumatology service in a UK hospital Selection random selection of eligible yp, (eligibility criteria not clear) Data collection semi struc interviews in own home Data analysis Colaizzi's 7 stage process Reliability + - Validity + choice of interview venue; 2 others analysed data as well - 'when yp lacked knowledge potentially leading to harm... time for discussion was made after the interview' p525 – was the interviewer their CSN? - Clinical view of care: patients must be 'specially trained' in order to 'effectively support others with the same illness in managing self-care'; policy has 'outlined plans for the enhancement of the patient role in care' p522'</p>	<p>Participants 6 y women 16-19 years Location UK Sample size SES/Ethnicity N/K</p>	<p>'All participants had read around their illness and the desire to learn was unanimously evident' p527 YP liked - When a doctor arranged for her to meet with another girl with lupus (contrary to yp with diab) - Pos'y (when pressed) more info on progression, duration of treatment and knowledge of famous people with arthritis – and possibly counselling might be helpful - Effective communication about their illness from clinicians - found useful information on their illness from GP, consultant, leaflets in clinic, Authors conclude the need for 'tailored services' and 'the potential for expert patient schemes' p530.</p>
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<p>33. Taylor, Franck, Dhawan, Gibson 2010 Liver transplant To explore in the depth the subjective aspects of yp's quality of life after transplant, where yp's</p>	<p>Design Recruitment via liver transplant centre Selection: purposive by age and chronic/acute /metabolic liver disease Data collection semi structured</p>	<p>Participants 14 Location N/K (UK) Children's age 12-18 Gender/ SES /</p>	<p>CYP (over 14 yrs – those younger didn't comment on HCP, author thinks pos because they are not included in consultations) found difficult - feeling local hospital staff had little understanding or experience of liver transplantation - The journey to the tertiary centre - Feeling information from doctors was inconsistent</p>
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<p>perception of their quality of life is understood as arising out of clinical factors relating to the transplant combined with factors relating to the young person.</p> <p>Rationale – quality of care will be judged in the UK on patients views of their experiences and outcomes from care (DH2008) . A step toward involving yp in service provision is ‘to understand their illness experience’.</p>	<p>interviews to ‘capture yp’s experiences of QoL firsthand... [and] ascertain yp’s knowledge of their illness’p1078</p> <p>Data analysis Framework</p> <p>Reliability + second researcher checked parts of analysis</p> <p>-</p> <p>Validity + yp could choose to be interviewed at home (all did); researcher had informal chat about non-health issues to put yp at ease; taped, fully transcribed</p> <p>-</p>	<p>Ethnicity N/K</p> <p>Other information Time since transplant was 10mths to 14.5 years</p>	<p>(eg around drinking alcohol) and advice not proactive</p> <ul style="list-style-type: none"> - Feeling torn between familiarity and continuity in paed services and wanting to transition to adult where they felt there might be better provision of ‘adult-type’ information eg sex (only raised by 17-18 yrs YP as the centre had no planned transition pathway] <p>CYP wanted</p> <ul style="list-style-type: none"> - Information about the transplant in a context with which they could identify... otherwise info just increased anxiety
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<p>34. Brewer, Smith, Eatough, Stanley, Glendinning, Quarrell 2007</p> <p>Juvenile Huntingtons</p> <p>Aims: to investigate the social and health care needs of those affected by JHD</p> <p>Rationale – social support is seen as ‘desirable’ though some ‘research highlights more negative aspects of some social interactions [as] a stressor rather than supportive... it would be useful to investigate which particular well-intentioned interactions are satisfying for individuals and which have the opposite effect p42’</p> <p>Mothers are often sole carers as HD from fathers</p>	<p>Design IPA</p> <p>Recruitment: 16 families identified via a national register of yp with JHD willing to be contacted about research; 2 families known to the researcher</p> <p>Selection: self-selecting parent/guardians</p> <p>Data collection semi struc interviews: 8 with one parent, 2 with both parents,</p> <p>Data analysis thematic</p> <p>Reliability + - Validity + taped, full transcription, interviews at home</p> <p>-</p>	<p>Participants 12 carers in 10 families with CYP with JHD, 8 mothers, 4 fathers (may be guardians rather than biolog parents)</p> <p>Location N/K UK</p> <p>SES/Ethnicity N/K</p> <p>Other information in 7 families children were teenagers, in one a child, and in 4 over 20 years; Author reports that in 10 families affected parents were fathers, 10 had died</p>	<p>Parents disliked professional support that</p> <p>Blamed them for child’s challenging behaviour eg parenting skills ‘this psychiatrist just tore us to shreds’ (child was misdiagnosed with dyspraxia initially)</p> <p>Not listening, nor believing eg receiving little support before confirmed diagnosis, having to fight to have their view heard, feeling judged eg ‘we did end up in a big meeting..’the court martial’ ... we had to stand in front of all these people... and they asked us question after question’</p> <p>Inflexibility eg dentist who expected boy with JHD to be able to sit still with his mouth open – gave impression he didn’t believe diagnosis; school unreasonable expectations ‘I’ve given up going to parents evenings. I find them so depressing’ p48</p> <p>Inconsistency / instability cos of high turnover of staff working with the family – difficult for children who find coping with change difficult</p> <p>Parents liked support from profs that was</p> <p>Active listening and believing</p> <p>Demonstrating that they understood families concerns (rather than questioning ‘what do you mean’)</p> <p>Being open and honest eg about not knowing much about the condition</p> <p>Consistent – eg social worker ‘he stuck in there, he stayed the course’</p> <p>Flexibility – being willing to ‘try anything’ ‘rather than there being fixed to one way of doing things’ – ‘open-minded to new ways of approaching a problem’ p47</p> <p>CONC – reiterate findings</p>
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<p>35. Williams et al 2011</p> <p>To identify:</p> <ul style="list-style-type: none"> • Types and characteristics of children’s health info resources available; and how they are used • Preferences about type of info/ format; diffs between CYP and families on these and diversity of 	<p>Design: Mixed (3 stages, including a qualitative component);</p> <p>Recruitment: hospital out-patient clinics, primary care and home settings, Medicines for Children Research Network (MCRN).</p> <p>Selection: CYP with a specified tracer condition/ long-term conditions/ acute conditions</p> <p>Data collection partial,</p>	<p>Participants: children age 6-18 years, family , HCP</p> <p>Location: not identified</p> <p>Sample size: 45 observations; 12 focus groups; 98 interviews;</p> <p>Children’s age:6-18</p>	<p>CYP wanted</p> <ul style="list-style-type: none"> - realistic and meaningful information that fits with their age, circumstances (family, home, school, college) and differing health needs along condition-specific trajectories -but they also want to choose from a selection that takes account of different perspectives across age range, which reflects individual interests beyond a focus on a specific disease; - high quality info , relevant, contemporary and shared at key points eg diagnosis, starting school, changing school, growing up with the condition, lifestyle issues and transition. - Written info to support verbal in consultations and needs to be more detailed (not basic), but less scientific (lay language) and up to date.
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<p>health information needs</p> <ul style="list-style-type: none"> Issues around when it is appropriate for CYP to be making choices about their care (at what developmental stage); and how this is negotiated between CYP and families and HCP <p>Rationale - Info is central to empowering CYP to have choice, make decisions, and learning to self-care in age-appropriate ways. But we know little about the types/delivery formats which support and empower CYP/families decisions and choices in self-care</p>	<p>scoping and illustrative review of lit; exploratory qual study inc 45 observations, 12 focus gps, in-depth interviews with 98 children and key family members</p> <p>Data analysis/synthesis: mixed-method evidence integration.</p> <p>Reliability:</p> <ul style="list-style-type: none"> + interview data analysis well described on p. 113; + facilitated by discussion; + use of coding frameworks; +and use of software +use of theoretical frameworks; <p>Validity</p> <ul style="list-style-type: none"> + clear methods reporting + extensive discussion of findings/implications -smaller sample than expected (p. 114; 219) 	<p>Gender: boys and girls</p> <p>SES: no information</p> <p>Ethnicity: CYP from minority ethnic backgrounds purposively sampled (p. 112) but no other information on ethnicity of respondents</p>	<p>- Access to specialist info from ‘experts’</p> <p>In relation to transition, environment in which care is given was described as noisy, busy, rushed, boring and daunting. CYP wanted more relaxed, less clinical environment (p. 165). Some children (especially teenagers) are uninterested in info and participation, whereas others valued and used specific health info to self-care.</p> <p>Observational data showed that ‘...the passage of children and young people through fairly rigid environmental and organisational ‘processes’ seemed at times to inhibit the fostering of a more child-centred approach’ (p.121). Excellent child-centred approaches were exception rather than rule (p.126).</p> <p>Parents actively sought additional info though some appeared overwhelmed by it.</p> <p>CONC - CYP health information resources need to be realistic, tailored and involve CYP in development. Written information should support verbal information and needs to be detailed but not too scientific and up-to-date. Specialist, expert information is key to complex and long-term conditions. CYP and families want to engage with empathic HCPs. Information facilitation needs to take account of CYP maturity, comprehension and receptivity. Good practice identified in some areas (Acute ENT surgery and Diabetes services). Reaching adolescence seemed particularly difficult for CYP with Diabetes and Cystic Fibrosis. .</p>
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<p>36. Shaw Southwood, McDonagh 2004 JIA transition</p> <p>To gain insight into the transitional needs of adolescence with JIA and examine how these needs may be addressed within a structured prog of transition</p> <p>Rationale – need an evidence base for developing transitional care; ‘the need to incorporate user perspectives... is increasingly espoused... discrepancies between adolescents’ actual health concerns and prof agendas for yp are well documented and there is a real danger than the marginalisation</p>	<p>Design Focus group discussion</p> <p>Recruitment via ‘participating hospitals’</p> <p>Selection : initially random invitations, then purposive selection from positive response to max variation by gender, SES, ethnicity, age, severity and duration of condition</p> <p>Data collection focus groups</p> <p>Data analysis IPA, constant comparative</p> <p>Reliability</p> <ul style="list-style-type: none"> + - <p>Validity</p> <ul style="list-style-type: none"> + researchers fed back summary 	<p>P/pants</p> <p>YP 12-30yrs and their parents (n=53)</p> <p>Location</p> <p>N Eng, S Eng, Midlands</p> <p>Gender</p> <p>YP 67% y women</p> <p>SES n/k</p> <p>Ethnicity</p> <p>YP 83% white</p> <p>Other informati on</p> <p>83% urban residence; median duration disease 5 yrs</p>	<p>Participants wanted transitional care to be</p> <ul style="list-style-type: none"> - centred on regular individualised assessments of yp’s disease status, developmental level, life event and personal aspirations - co-ordinated by a multi-disciplinary team with specialist JIA knowledge and strong interagency links esp with GPs and schools, and earlier referrals (not clear if this means to adult services or something else) and greater signposting of information (?) with a named key worker/co-ordinator as first point of access in a crisis - consent for students to observe consultation sought in waiting room beforehand, and that they are present only part of consultation - adol-focussed clinics, wards and waiting rooms which they felt would facilitate peer support - more flexible appts to minimise missing school/work – drop-in might minimise DNA - information on functional ability, treatments, psychological health, social and parental issues (eg impact on family and minimising impact on valued activities), education, vocation (appropriate career choices), independent living inc benefits, housing/driving, skills for independence, sexual relationships inc disclosure, sexual health/contraception, parenting, genetic risk (parents wanted to gate-keep yp access to info on side effects, but yp didn’t want either prof or parents to act as gatekeepers to any info) - communication that is honest, realistic and jargon-free - for YP: HCP who make effort to ‘lessen the inequalities between them by making the environment less formal, asking about non-medical aspects of their lives and sharing personal information’; who sought their consent and respected their decisions (tho they were unclear about their rights to accept/refuse treatment); who supported their confidence in their ability to advocate for themselves in lone consultations - begin prep for transfer early by learning to have lone consultations and so feeling in control and independent - transition arrangements where they could stay with their same health care team - YP wanted flexibility about time of transfer determined by individual readiness and shared decisions-making but parents felt it should be done by the time yp were 18, though if they had a crisis often wanted to return to paed <p>Participants did not like</p> <ul style="list-style-type: none"> - strangers in consultations (students) esp if they just observed and didn’t contribute: implied consultation for HCP not yp; felt invasion of privacy and threat to confidentiality - yp said they were asked for consent and found difficult to refuse
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<p>of yp's views may result in policies and practices that have little meaning for those that they are intended to benefit' p770</p>	<p>findings at conclusion of group for amendment, comment, prioritisation, taping, full transcription; non-directive facilitation; negative case analysis - differentiation btw grps needs to be clear eg YP/carers</p>		<ul style="list-style-type: none"> - their experiences of transition which were sudden and ill-prepared – felt 'abandoned' esp those who had to change consultant or who had strong reln with paed staff - YP feeling their adulthood not recognised by staff who'd known them as children and who remained responsible for their care into adult services - perceived low levels of expertise, empathy and resources in adult services (eg no longer qualified for hydrotherapy) compared to paed (and high numbers of old people) - delays in transfer, discontinued care and cancelled appts because of poor co-ordination - yp did not like managing consultations alone or found it difficult if they relied on parents to transport to refuse them coming into consultation - Parents feared yp would not know how to 'use the consultation to their best advantage' and though they recognised the importance of yp learning to attend alone felt ch didn't always give a true representation of their health status <p>CONC – authors feel because YP concerns with confidentiality, good information and staff friendliness chime with concerns of 'healthier' yp, they are likely to be generalizable over other conditions.</p>
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<p>37. Kirk 2008 What are CYP w complex needs experiences of moving from child to adult services and moving from parental care to self-care. Rationale - We have evidence on parents exp of transition but little of CYP not least because they 'are a relatively new gp of children... surviving to adulthood' p568; key elements of effective transition are known (multi-agency, person-centred planning, co-ordination of services, and continuity, involvement of CYP and families and dedicated transition support). But, there is little evidence on which to build service models</p>	<p>Design not explicit Recruitment via CCN Selection purposive by age, and medical technology Data collection face to face in-depth interviews at home Data analysis grounded theory Reliability + - Validity + flexible interviews at home; full transcription, taped -</p>	<p>Participants 28 YP with complex healthcare needs or where CYP did not use verbal or alternative communication, parents were key informants (n=9) Location NW England Children's age 8-19 yrs Gender/SES/Ethnicity N/K</p>	<p>YP need transition care that Acknowledges multiple concurrent transitions in 'life' (childhood to adulthood) at same time as organizational/ illness transitions. YP disliked how service transition was hard because of - poor information and involvement in planning and lack of formalised processes to support this - sudden unexpected change, and worry about continuity of support packages into adult services and whether specialist expertise would be available at all. While learning responsibility for managing therapies and devices was evolving, individually negotiated, responsibility for decision-making and liaising with services could be acquired suddenly on transfer to adult services and not as part of an integrated self-care transition process. - having to adjust in adult care to a different (less 'cossetted') culture, more 'depersonalised' environment and way of working and loss of relationships with familiar, trusted HCP. 'They had to adjust to their involvement in decision-making being encouraged' p569 CONC – individualised person-centred assessment and planning is especially important for yp with complex conditions at multi-agency and specialist care level as many have conditions and support needs unfamiliar to adult care providers eg costly/complex home support packages. 'CYP were not well prepared during their time in children's services for becoming increasingly involved in decision making and in consultations with HCP... access to support from independent advocates may be appropriate' p574.</p>
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<p>38. Miles et al 2004 To explore YP experience of transition from paed to adult HIV care. 'the general complicating factors during transition such as lifetime changes in schooling, employment, leaving home, new social opportunities, and developing independence can be further complicated</p>	<p>Design not explicit Recruitment via adult HIV outpatients Mortimer Market Centre Selection YP who had transitioned from GOS paed unit to the MMC Data collection single semi</p>	<p>Participants 7 YP aged 16-22 Location central London provider Children's age Gender 5 men, 2 women SES n/k Ethnicity 4 'UK born', 3 'African' Other information Transitioned with past 2 years when 16-</p>	<p>YP liked - existing established process beneficial especially intro to adult service early on in transition prep period - sense of independence, shift in responsibility to themselves and general satisfaction in being treated as an adult. Some yp had concerns about - co-ordination of haemophilia and HIV care (haemophilia adult care in different building) - fear of adult services eg being judged about origin of HIV; or seeing adults with HIV illness would remind them of the increased likelihood of illness with age - YP who'd been more involved in planning their paed care</p>
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for YP living with HIV.. but little is known about adolescents who transition between paed and adult HIV care in UK 'p305-6	structured interview Data analysis thematic Reliability + - Validity + taped and full transcription -	20 years, 1-20 yrs in paed care; 3 infected by blood products, 4 vertical transmission; all diagnosed as infants except one at 15 yrs. Knew about status: 5 yrs to 18 years	were more concerned about the move than others as confidence and attachment to staff was higher - not prepared for the mainly gay male population in adult care - not to see other yp in adult services CONC increasing numbers of yp surviving into adulthood means providers need to take into account yp changing needs and ensure transition is purposeful, planned and effective.
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Allen D, Channon S, Lowes L, Atwell C, Lane C. Behind the scenes: the changing roles of parents in the transition from child to adult diabetes service. *Diabetic Med.* 2011;28(8):994-1000.

Allen D, Cohen D, Hood K, Robling M, Atwell C, Lane C, et al. Continuity of care in the transition from child to adult diabetes services: a realistic evaluation study. *J.Health Serv.Res.Policy* 2012 Jul;17(3):140-148

Brewer HM, Smith JA, Eatough V, Stanley CA, Glendinning NW, Quarrell OW. Caring for a child with Juvenile Huntington's Disease: helpful and unhelpful support. *J.Child Health Care* 2007 Mar;11(1):40-52

Brooks F, Bloomfield L, Offredy M, Shaughnessy P. Evaluation of services for children with complex needs: mapping service provision in one NHS Trust. *Primary health care research & development* 2013;14(01):52-62.

Carter B, Cummings J, Cooper L. An exploration of best practice in multi-agency working and the experiences of families of children with complex health needs. What works well and what needs to be done to improve practice for the future? *J.Clin.Nurs.* 2007;16(3):527-539.

Cejer B. The needs and experiences of long-term ventilated children and their families. *Paediatric Nursing* 2007 19(5): 42-4

Curtis-Tyler K. Facilitating children's contributions in clinic? Findings from an in-depth qualitative study with children with Type 1 diabetes. *Diabetic Med.* 2012;29(10):1303-1310.

Curtis-Tyler K. Levers and barriers to patient-centred care with children: findings from a synthesis of studies of the experiences of children living with type 1 diabetes or asthma. *Child: care, health and development* 2011;37(4):540-550.

Dovey-Pearce G, Hurrell R, May C, Walker C, Doherty Y. Young adults'(16–25 years) suggestions for providing developmentally appropriate diabetes services: a qualitative study. *Health & social care in the community* 2005;13(5):409-419.

Edgecombe K, Latter S, Peters S, Roberts G. Health experiences of adolescents with uncontrolled severe asthma. *Arch.Dis.Child.* 2010 Dec;95(12):985-991

Eiser C, Johnson B, Brierley S, Ayling K, Young V, Bottrell K, et al. Using the Medical Research Council framework to develop a complex intervention to improve delivery of care for young people with Type 1 diabetes. *Diabetic Med.* 2013;30(6):e223-e228.

Forsey M, Salmon P, Eden T, Young B. Comparing doctors' and nurses' accounts of how they provide emotional care for parents of children with acute lymphoblastic leukaemia. *Psycho-Oncology* 2013;22(2):260-267.

Hummelinck A, Pollock K. Parents' information needs about the treatment of their chronically ill child: A qualitative study. *Patient Educ.Couns.* 2006;62(2):228-234.

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):521-533.

Kirk s Transitions in the lives of yp with complex healthcare needs [Child Care Health Dev.](#) 2008 Sep;34(5):567-75. doi: 10.1111/j.1365-2214.2008.00862.x.

- Kirk S, Beatty S, Callery P, Milnes L, Prymachuk S. Perceptions of effective self-care support for children and young people with long-term conditions. *J.Clin.Nurs.* 2012;21(13-14):1974-1987.
- Lewis SA, Noyes J, Mackereth S. Knowledge and information needs of young people with epilepsy and their parents: Mixed-method systematic review. *BMC Pediatr.* 2010 Dec 31;10:103-2431-10-103
- Lowe R, Bravery K, Gibson F. Navigating the maze: parents' views and influence on a paediatric haematology and oncology day care service. *J.Clin.Nurs.* 2008;17(23):3159-3167.
- Lowes L, Lyne P, Gregory J. Childhood diabetes: parents' experience of home management and the first year following diagnosis. *Diabetic Med.* 2004;21(6):531-538
- Lyte G, Milnes L, Keating P, Finke A. Review management for children with asthma in primary care: a qualitative case study. *J.Clin.Nurs.* 2007;16(7b):123-132.
- Maddox C, Pontin D. Paid carers' experiences of caring for mechanically ventilated children at home: implications for services and training. *J.Child Health Care* 2013 Jun;17(2):153-16
- Marshall M, Gidman W, Callery P. Supporting the care of children with diabetes in school: a qualitative study of nurses in the UK. *Diabetic Med.* 2013;30(7):871-877.
- Miles K¹, Edwards S, Clapson M. *AIDS Care.* 2004 Apr;16(3):305-14. Transition from paediatric to adult services: experiences of HIV-positive adolescents..
- Newbould J, Francis SA, Smith F. Young people's experiences of managing asthma and diabetes at school. *Arch.Dis.Child.* 2007 Dec;92(12):1077-1081
- Noyes J. Health and quality of life of ventilator-dependent children. *J.Adv.Nurs.* 2006;56(4):392-403
- Pontin D, Lewis M. Maintaining the continuity of care in community children's nursing caseloads in a service for children with life-limiting, life-threatening or chronic health conditions: a qualitative analysis. *J.Clin.Nurs.* 2009;18(8):1199-1206.
- Pontin D, Lewis M. Managing the Caseload: A Qualitative Action Research Study Exploring How Community Children's Nurses Deliver Services to Children Living With Life-Limiting, Life-Threatening, and Chronic Conditions. *Journal for Specialists in Pediatric Nursing* 2008;13(1):26-35.
- Price C, Corbett S, Lewis-Barned N, Morgan J, Oliver L, Dovey-Pearce G. Implementing a transition pathway in diabetes: a qualitative study of the experiences and suggestions of young people with diabetes. *Child: care, health and development* 2011;37(6):852-860.
- Santer M, Burgess H, Yardley L, Ersser S, Lewis-Jones S, Muller I, et al. Experiences of carers managing childhood eczema and their views on its treatment: a qualitative study. *Br.J.Gen.Pract.* 2012 Apr;62(597):e261-7
- Shaw KL Southwood TR, McDonagh JE; Rheumatology (Oxford). 2004 Jun;43(6):770-8. Epub 2004 Mar 23. User perspectives of transitional care for adolescents with juvenile idiopathic arthritis.
- Shepherd JM. Younger children's nursing students are uniquely placed to provide emotional care for young people in hospital and promote for them a sense of normalcy. *Nurse Educ.Today* 2014;34(6):1034-1039.
- Shilling V, Edwards V, Rogers M, Morris C. The experience of disabled children as inpatients: A structured review and synthesis of qualitative studies reporting the views of children, parents and professionals. *Child: care, health and development* 2012;38(6):778-788.
- Smith F, Taylor K, Newbould J, Keady S. Medicines for chronic illness at school: experiences and concerns of young people and their parents. *J.Clin.Pharm.Ther.* 2008;33(5):537-544.
- Soanes C, Timmons S. Improving transition: a qualitative study examining the attitudes of young people with chronic illness transferring to adult care. *J.Child Health Care* 2004 Jun;8(2):102-112

Swallow VM, Nightingale R, Williams J, Lambert H, Webb NJ, Smith T, et al. Multidisciplinary teams, and parents, negotiating common ground in shared-care of children with long-term conditions: A mixed methods study. BMC health services research 2013;13(1):1-17.

Taylor RM, Franck LS, Dhawan A, Gibson F. The stories of young people living with a liver transplant. Qual. Health Res. 2010 Aug;20(8):1076-1090

Taylor RM, Gibson F, Franck LS. The experience of living with a chronic illness during adolescence: a critical review of the literature. J.Clin.Nurs. 2008;17(23):3083-3091.

Williams. Children's Health Information Matters: Researching the practice of and requirements for age appropriate health information for children and young people http://www.netscc.ac.uk/hsdr/files/project/SDO_FR_08-1718-145_V01.pdf