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# School lives of adolescent school students living with chronic physical health conditions: a qualitative evidence synthesis

Bethan K C Spencer,<sup>1</sup> Judy Wright,<sup>1</sup> Kate Flemming,<sup>2</sup> David Cottrell ,<sup>1</sup> Simon Pini <sup>1</sup>

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<sup>1</sup>Leeds Institute of Health Sciences, University of Leeds, Leeds, UK

<sup>2</sup>Department of Health Sciences, University of York, York, UK

## Correspondence to

Dr Simon Pini, Leeds Institute of Health Sciences, University of Leeds, Leeds, West Yorkshire, UK; [S.Pini@leeds.ac.uk](mailto:S.Pini@leeds.ac.uk)

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## ABSTRACT

**Objective** Assess the existing evidence base in order to synthesise the current qualitative findings for the impact of chronic health conditions on the school lives of young people.

**Design** Qualitative evidence synthesis using thematic synthesis.

**Patients** Young people aged 11–18 years with a chronic health condition from one of the following groups: oncology, cystic fibrosis, diabetes, asthma, rheumatology, neuromuscular, colorectal, chronic pain, allergies and dermatology.

**Outcome measure** Qualitative findings and discussions present in included studies formed the data for the thematic synthesis.

**Results** From a search identifying 19311 records, a sample of 35 papers were included. The included papers represented 15 countries and primarily employed interviews as part of data collection. Thematic synthesis resulted in six themes: 'keeping up/catching up/missing out/looking forward'; 'identity'; 'relationship with peers'; 'normality and difference'; 'autonomy'; 'relationships with staff'.

**Conclusions** Thematic synthesis highlighted the commonalities, rather than divergence, of issues for young people across different chronic conditions. Policies need to be based on the experiences of the people they aim to provide for, and while attendance and attainment remain important, there is clearly more that needs to be considered when gathering data, designing interventions and developing policies to support this population. It may also be advisable for clinical professionals to include the broader psychosocial aspects of school life in discussions and plans to support young people with long-term conditions.

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## INTRODUCTION

Chronic physical health conditions are defined as those requiring ongoing management over a period of years that can be controlled, but not cured, with the use of medication and other therapies.<sup>1 2</sup> However, there is inconsistent use of terminology across the field when definitions are created through the lens of different specialisms.<sup>3</sup> Taking into account the variety of definitions, it is estimated that 13%–27% of children are affected by chronic conditions.<sup>4</sup> In the UK, this figure is approximately 1–1.7 million.<sup>5–8</sup>

Most research into the impact of chronic health conditions on education focuses on quantitative outcomes of school attendance and attainment and

## WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ The majority of research into education outcomes for young people with long-term conditions is disease specific and focuses on attendance and attainment. Qualitative research in this topic is disparate and requires synthesis to establish commonalities.

## WHAT THIS STUDY ADDS

⇒ Thematic synthesis resulted in six themes reflecting commonalities in the findings of studies from diverse health conditions: keeping up/catching up/missing out/looking forward, identity, relationship with peers, normality and difference; autonomy and relationships with staff.

## HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ Policy and practice need to focus on diverse aspects of school life beyond attendance and attainment. The commonalities in the findings also suggest that cross-condition working is the desirable direction for future research and policy development.

concludes that outcomes are negatively impacted by a chronic health condition to varying degrees.<sup>9–17</sup> For example, studies conducted in childhood epilepsy, diabetes and asthma all showed relative deficits in educational attendance or attainment.<sup>10–12</sup>

However, attainment and attendance do not tell us how school life is experienced by young people with chronic conditions. The aim of this review of qualitative research was to establish what current research tells us about the experience of school life for young people with a chronic condition in 1 of 10 clinical groups. The review focuses on the UK age range for high school, which is 11–18 years. The results inform the initial stage of a wider project (the INSCHOOL project) to develop impactful policies, support and screening assessments that are grounded in the experiences of young people.

## METHOD

### Research question

What do high school pupils say about the impact their health condition has on their school lives?



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## Design

A qualitative evidence synthesis using thematic synthesis.<sup>18</sup>

## Search strategy

In September 2021, comprehensive searches of 13 databases and a search engine were conducted for qualitative studies on the impact of chronic or life limiting health conditions on high school lives (see online supplemental file 1).

Searches were developed for: adolescents, school settings, 10 chronic conditions, outcomes covering quality of life, education and psychological, and qualitative methods. Subject headings and free text words were identified from relevant papers by JW and SP. The filters described by DeJean *et al*<sup>19</sup> were applied with minor adaptations for qualitative papers (online supplemental file 1 reports full search strategy). Bibliographies were scrutinised for further studies. Results were deduplicated in EndNote (X9) before being transferred to Covidence for screening and data extraction.

## Inclusion criteria

- ▶ Qualitative methods.
- ▶ First-hand accounts from young people aged 11–18 years.
- ▶ Data related to school life.
- ▶ The INSCHOOL project is working directly with young people and clinicians from children's services in a parallel qualitative project in a large urban setting in the north of England. To align with this project, and to represent diversity of visibility, severity and predictability, the following health conditions have been included in the current review:
  - Oncology.
  - Cystic fibrosis.
  - Diabetes.
  - Asthma.
  - Rheumatology.
  - Neuromuscular.
  - Colorectal.
  - Chronic pain.
  - Allergies.
  - Dermatology.

## Study screening methods

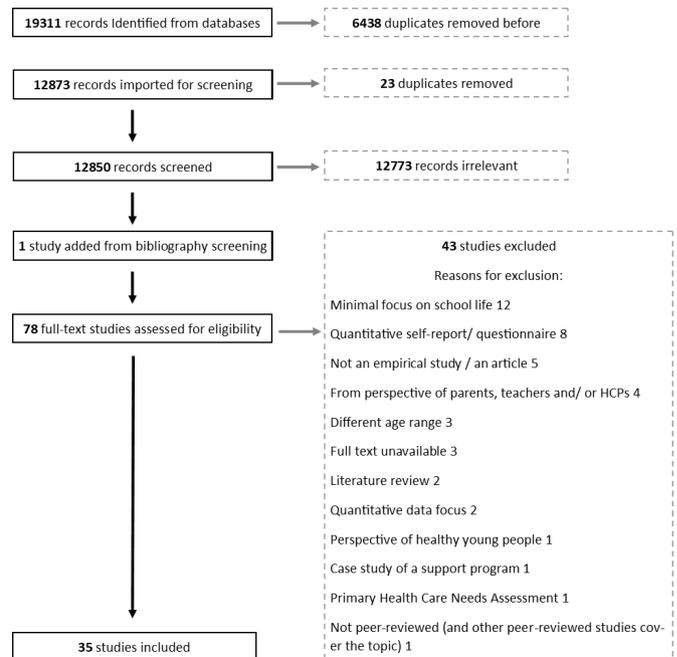
Title screening was conducted by BKCS, with marginal cases discussed with SP, followed by abstract screening by both. Full texts were then reviewed by BKCS and SP who judged inclusion independently before resolving discrepancies. Appraisal was guided by pragmatic assessment of content and utility of findings related to the research question. The school lives of young people with chronic health conditions did not have to be the primary focus of the research, provided that the findings were relevant to the review.

## Appraisal items

CASP Qualitative Studies Checklist<sup>20</sup> was used to assess methodological quality. BKCS and SP applied this checklist alongside data extraction and resolved uncertainties. A-priori cut-off criteria were not set, as the review aimed for inclusivity of relevant findings. Papers with multiple answers of 'no' or 'unsure' were reviewed with for exclusion.

## Data extraction

BKCS and SP conducted data extraction independently and resolved discrepancies. Essential contextual information and methodological detail were extracted using a study-specific data



**Figure 1** PRISMA diagram. PRISMA, Preferred Reporting Items for Systematic Reviews and Meta-Analyses.

extraction form. In preparation for thematic synthesis, results and discussion sections were the primary source of findings, alongside quotes from participants and authors. These sections were approached line by line and scrutinised for relevant content.

## Synthesis methodology

Thematic synthesis drew together findings across studies into descriptive and analytic themes. Analysis was inductive and sought to critically approach extracted data independent of original author interpretation. This allowed novel concepts and interpretations to arise. Synthesis began using a group of four papers to establish a first draft of the thematic framework. These papers were identified during full-text review as most relevant to the research question. The initial framework was then applied to remaining papers in an iterative process of refinement through discussion of negative cases and emerging concepts.

## RESULTS

### Study selection results

From a search identifying 19311 records, 35 papers were included. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses diagram details how studies were excluded (figure 1).

### Study characteristics

Included papers represented 15 countries spanning 1995–2021. The majority (32/35 studies) employed interviews. Details are presented in online supplemental file 2.

### Appraisal results

No a-priori cut-offs were used. Following review of the CASP checklist with the research team, it was decided no studies needed to be excluded based on methodology. Full study appraisal can be found in online supplemental file 3.

## Synthesis output

Assessment of the four most relevant papers produced 16 descriptive themes, which were developed into an initial framework of six overarching analytical themes. These were further refined through iterative application to the remaining papers. The six analytical themes remained stable, with each paper adding richness to the themes rather than producing new thematic directions (thematic contribution displayed in online supplemental file 4).

Thematic synthesis resulted in six themes:

- ▶ Keeping up/catching up/missing out/looking forward.
- ▶ Identity.
- ▶ Relationship with peers.
- ▶ Normality and difference.
- ▶ Autonomy.
- ▶ Relationships with staff.

Each theme is detailed with reference to relevant participant/author extracts (further extracts can be found in online supplemental file 5).

### Keeping up/catching up/missing out/looking forward

Absence was a key aspect of managing education.<sup>21–30</sup> Maintaining education in spite of absences was important to young people and staying connected with school benefitted students.<sup>26 31–35</sup> Lakeman highlighted ‘*keeping up*’, ‘*catching up*’ and ‘*missing out*’, which are core concepts reflected in 31 of the papers and highlighted by shortened lessons, leaving early or missing school for treatment.<sup>24 27 28 36</sup> However, even when able to attend school, difficulty concentrating, fatigue and pain made remaining engaged in lessons a struggle.<sup>23 26 36–39</sup> ‘*Missing out*’ was not only related to school work, but also school trips, social and physical activities<sup>27 33 38 40</sup> and could affect social involvement, leaving young people ‘*out of the loop*’.<sup>21 22 26 27 29 36–38 41–43</sup>

Underlying the ‘*burden*’<sup>36</sup> of catching up was concern about falling behind in school and the potential impact on attainment.<sup>21 23–25 33 36 38 39 44 45</sup> Studies reported concerns related to pressure from themselves and others,<sup>23 39 46</sup> a lack of confidence,<sup>23</sup> a lack of provisions<sup>31</sup> or feeling excluded from the curriculum.<sup>27</sup> Exams and grading were often benchmarks of ‘normal’ progress or keeping up with peers, as well as a means of shaping the future.<sup>46</sup> Young people expressed concerns they would be lacking certain skills as a result of missed school.<sup>33 44 47</sup> However, many had focused long-term goals for their education and career, often influenced by their experience of living with a health condition.<sup>32 38 47</sup> There were examples where health experiences were constructively incorporated into future plans and others where these plans were in defiance of the limitations they had faced.<sup>32</sup>

### Identity

Studies suggested the importance of acknowledging that secondary school years are a time when self-identity develops, particularly in context of the school environment.<sup>32 48</sup> The emergence of various identities as an adolescent and student can remain separate from, or intertwined with a young person’s chronic health condition.<sup>32 47–49</sup> While Cotter (2016) found a young person’s identity as a student develops separately from their chronic condition identity (cystic fibrosis), other studies found young people’s identities merge with their condition, in more profound cases leading to a sense of losing a former self, or life being ‘*ruled by illness*’.<sup>50 22 26 49 50</sup> For some, this meant distancing themselves from condition labels, the ‘*sick-patient*

role and ‘*personal tragedy*’<sup>47 49</sup> and wanting to ‘*remain the same but changed*’.<sup>46</sup>

Some young people referred to ‘*visible differences*’ such as hair loss,<sup>25 33 36</sup> weight loss,<sup>32</sup> mobility difficulties<sup>38</sup> and scars<sup>32</sup> as a result of their condition.<sup>32 38 43</sup> Such changes in appearance could shape school experiences by providing a ‘*before and after*’ during reintegration.<sup>46</sup> Visible changes could result in unwanted attention and altered peer dynamics, and young people reported hiding visible differences.<sup>24 36 41 46</sup> To compound this issue, several studies reported the negative impact of school staff projecting a ‘*disabled identity*’<sup>38</sup> or ableist attitudes onto the young people.<sup>38 47 50</sup>

### Relationships with peers

Peer groups are a central aspect of school life and an important source of practical and emotional support.<sup>21 22 25 26 28 29 31 32 35 37 38 40 41 43–46 48 51 52</sup> Young people express a desire for ongoing contact and social acceptance within school.<sup>24 25 35 46 47</sup> Exclusion from social groups could result in feelings of isolation, alienation and invisibility.<sup>22 26 31 36 38 47</sup> Young people highlighted the distressing effect of being ignored and a lack of understanding and empathy from peers.<sup>21 27 31 53</sup> who could see conditions as ‘*disgusting*’ or ‘*strange*’<sup>50</sup> and, in some cases, result in physical and verbal bullying.<sup>25 27 32 40 41 43 50</sup> Young people with health conditions were often the focus of increased attention from peers and found themselves explaining their condition, sometimes repeatedly, and subject to curiosity and questioning.<sup>27 36 47 48 54</sup> Some saw this as a chance to help others understand and to ensure correct information was shared, but many found it frustrating, exhausting and ineffective,<sup>21 42 48 54</sup> especially coping with disproportionately emotional or negative responses.<sup>23 25 38 41 54</sup>

### Normality and difference

Overall, young people expressed a wish to be treated the same as healthy peers and to be perceived as normal,<sup>24 32 37 41 49 53</sup> although this was often not the case.<sup>23 25 31 38 54</sup> There was also tension between a desire for normality and a need for some special consideration.<sup>22 38 46 49</sup>

For many, school represented a stabilising environment with the potential for them to cultivate a return to normality after diagnosis<sup>25 32 33 43</sup> or redefine normal in their own way.<sup>33 45</sup> However, there are many challenges to the desire for normality in school and multiple studies referred to young people’s sense of difference or ‘abnormality’.<sup>22 24 38 40 43 45 47 51 54</sup> Some approached this by concealing their condition in order to ‘*act normally*’ or ‘*pass as normal*’.<sup>37 47 53</sup> Ferguson and Walker<sup>32</sup> highlighted this approach to normality meant some young people ‘*slipped under the radar*’.

### Autonomy

Studies reported feelings of reduced independence at a time when it was an important developmental milestone<sup>33 38 45 49</sup> and school was identified as providing an opportunity to regain independence and a sense of freedom.<sup>45</sup> Young people reported finding self-management, such as carrying and taking medication in school, a means of gaining independence, but this has been described as a challenging responsibility.<sup>37 38 41 42 47 50 51</sup> Young people wished to have easy access to medication, and the option of private safe spaces.<sup>37 40 47 55</sup>

Disclosure and controlling the narrative of their health condition was a significant factor in autonomy within school.<sup>33 38 41 42 48 54</sup> Some young people chose not to disclose

their health condition, or only disclosed when necessary,<sup>24 43 48</sup> whereas others were comfortable with disclosure.<sup>29 43 54</sup> Being involved in the process of sharing their ‘story’ was an important aspect of managing chronic health within school,<sup>26 27 33 54</sup> as young people could have some control of their own information, be able to shape a positive outlook and minimise rumours.<sup>33 54</sup>

In some studies, young people wanted to be heard in decision making and expressed a preference for person-centred practice, which was often absent.<sup>26 27 38</sup> Studies revealed that young people valued having knowledge and understanding of their condition, with some seeing educating others as empowering in the school environment.<sup>24 41 55</sup>

### Relationships with staff

Teachers having awareness and, in some cases, experience of their condition was an important factor in feeling supported at school.<sup>27 28 31 37 38 50 55</sup> Two studies suggested that more education for school staff on how to manage the health needs of young people is needed, as many staff do not know how to ‘deal with them’.<sup>29 55</sup> Young people valued empathetic teachers, those who reacted supportively to disclosure and were willing to make adjustments.<sup>24 27 31 32 38 50 51 53</sup> This could be enhanced by having one key member of staff offering support.<sup>24 25 27</sup>

Conversely, teachers lacking awareness and empathy had a negative impact on students’ school lives.<sup>27 38 50</sup> In some cases, teachers considered provisions to be ‘*so much fuss*’<sup>50</sup> and young people faced disbelief for the impact of their conditions, especially when there were few visible aspects.<sup>30 40 50</sup> This could lead to avoiding asking for help, feelings of isolation and concealment of symptoms in order to avoid stigma and judgement from teachers.<sup>22 40 53</sup>

The quality of communication and maintaining contact was important to students and affected the extent to which they felt cared about.<sup>34 35 46</sup> In some studies, the communication between healthcare professionals and teachers was inadequate or absent, meaning parents or motivated individual teachers assumed responsibility for this role.<sup>27 37 55</sup>

## DISCUSSION

This review has highlighted important themes present in the school experiences of young people across diverse chronic conditions. Themes were developed from papers focusing on different chronic conditions and highlight the commonalities, rather than divergence, of issues for young people regardless of condition. However, more focused work needs to be conducted in this area to highlight where specific conditions may result in specific challenges. It may be advisable for professionals and services, whether clinical or educational, to include the broader psychosocial aspects of school life in discussions and plans to support young people with long-term conditions. It is feasible that attending to the breadth of these issues has potential to improve the long-term educational, psychosocial and physical outcomes for this population, but more research will be needed in this area.

Policies need to be based on the experiences of the people they aim to provide for,<sup>56</sup> and while attendance and attainment remain important, there is clearly more that needs to be considered when gathering data, designing interventions and developing policies to support this population. Data related to important holistic aspects of the school lives of young people, such as peer relationships, autonomy and normality, are not gathered and integrated into education datasets. This is further complicated for young people with chronic health conditions, as

there is also a lack of integration of health and education data. Therefore, if policies and markers of progress are driven and evaluated by data, but the datasets are missing holistic psychosocial and health information, there is an increased chance of marginalising young people with chronic conditions.

More research is needed to further investigate the holistic and psychosocial needs of young people with chronic health conditions at school. Holistic data need to be gathered and integrated into education datasets to enable more informed policy making, more accurately targeted interventions and more nuanced evaluation of outcomes.

### Strengths and limitations

This review uniquely synthesised qualitative evidence across chronic conditions and presented important insights into the school experiences of this population. However, the intentional breadth of this review means there are several areas requiring more focused future research and elaboration.

**Contributors** BKCS: conducted the majority of screening, data extraction, quality assessment and synthesis. She produced first drafts of the results and contributed to refining and approving the final manuscript. JW: designed and conducted the search strategy, supervised the screening process, wrote sections of the methods and contributed to refining and approving the final manuscript. KF: provided training and supervision for the synthesis and contributed to refining and approving the final manuscript. DC: supervises the overall research programme, provided regular guidance on the direction of the paper and contributed to refining and approving the final manuscript. SP is the principal investigator for this workstream and the broader fellowship programme, is guarantor for the paper, designed the search strategy with JW, supervised BKCS, wrote first drafts of all sections of the paper excluding the results and led the final draft of the manuscript.

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### ORCID iDs

David Cottrell <http://orcid.org/0000-0001-8674-0955>

Simon Pini <http://orcid.org/0000-0001-8455-3240>

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**INSCHOOL Search Strategy****12/09/2021**Sources of published and grey literature

<b>Content Type</b>	<b>Source Name and platform (or URL)</b>
Published literature only	CINAHL (EBSCOhost)
	Cochrane Database of Systematic Reviews (Wiley) Issue 9 of 12, September 2021
	Core Collection (Web of Science) SCI-EXPANDED 1900+, SSCI 1900+, and ESCI 2015+ searched simultaneously.
	Education Abstracts (H.W. Wilson) (EBSCOhost)
	Ovid MEDLINE(R) ALL 1946 to September 16, 2021
Published and grey literature	Embase Classic+Embase (Ovid) 1947 - 2021 September 16
	ERIC (EBSCOhost)
	Google Scholar <a href="https://scholar.google.com/">https://scholar.google.com/</a>
	Social Care Online <a href="https://www.scie-socialcareonline.org.uk/">https://www.scie-socialcareonline.org.uk/</a>
Grey literature only	Core Collection (Web of Science) CPCI-S 1900+ and CPCI-SSH 1900+ searched simultaneously.
	ETHOS E-Theses Online Service <a href="https://ethos.bl.uk/Home.do">https://ethos.bl.uk/Home.do</a>

Ovid MEDLINE(R) ALL &lt;1946 to September 10, 2021&gt;

- 1 exp qualitative research/ 67321
- 2 "Surveys and Questionnaires"/ 508848
- 3 exp interview/ 29874
- 4 interview\*.tw,kf. 393491
- 5 qualitative.tw,kf. 265881
- 6 questionnaire\*.tw,kf. 571774
- 7 survey\*.tw,kf. 721796
- 8 ethnolog\*.mp. 171458

9	ethnograph*.mp.	12147
10	ethnonursing.af.	125
11	phenomenol*.af.	29629
12	(grounded adj (theor\$ or study or studies or research or analys?s)).af.	13324
13	(emic or etic or hermeneutic* or heuristic* or semiotic*).af.	19853
14	(data adj1 saturat*).tw,kf.	1545
15	participant observ*.tw,kf.	4950
16	action research.mp.	4761
17	(cooperative inquir* or co-operative inquir*).mp.	78
18	((purpos* adj4 sampl* or (focus adj group*)).af.	75046
19	(life world or life-world).mp.	366
20	conversation analys?s.mp.	780
21	personal experience*.mp.	14906
22	theoretical saturation.mp.	247
23	cluster sampl*.mp.	8253
24	observational method*.af.	855
25	content analysis.af.	33730
26	((discourse* or discours*) adj3 analys?s).tw,kf.	2707
27	narrative analys?s.af.	1527
28	or/1-27 [Adapted De Jean Qualitative studies filter]	1949143
29	(Chronic* adj2 (disease* or health or illhealth or condition or illness*)).tw,kf.	261058
30	(chronic* adj2 pain*).tw,kf.	63122
31	(long-term adj2 (disease* or health or illhealth or condition? or illness* or pain*)).tw,kf.	26499
32	asthma?.tw,kf.	157841
33	(broncho* or bronchial*).tw,kf.	197052
34	(cancer* or carcinoma* or neoplas* or adenocarcinoma* or malignan* or tumo?r* or sarcoma*).tw,kf.	3654018
35	(cystic* adj3 fibros*).tw,kf.	47929
36	(fibrocystic adj8 disease adj8 pancreas).tw,kf.	214
37	diabet*.tw,kf.	690969
38	eczema*.tw,kf.	20977

- 39 (rheumatoid\* adj2 arthriti\*).tw,kf. 117161
- 40 rheumati\*.tw,kf. 61294
- 41 (muscular\* adj2 (syndrome\* or condition? or disease\*)).tw,kf. 3075
- 42 (neuromusc\* adj2 (syndrome\* or condition? or disease\*)).tw,kf. 7908
- 43 Motor neuron disease.tw,kf. 5235
- 44 ("peripheral neuropathy" or "muscular dystrophy" or fibromyalgia).tw,kf. 55253
- 45 ((bowel\* or colon\* or intestinal or rectal\* or anal) adj2 (disease? or syndrome? or condition?)).tw,kf. 90759
- 46 ((skin or dermat\*) adj2 (disease? or condition? of syndrome?)).tw,kf. 37404
- 47 (allergy or allergies or allergic reaction? or hypersensitiv\*).tw,kf. 175885
- 48 exp Asthma/ or Bronchial Spasm/ or exp Bronchoconstriction/ or Bronchial Hyperreactivity/ or Respiratory Hypersensitivity/ 147212
- 49 exp Neoplasms/ 3532612
- 50 exp Diabetes Mellitus/ 454034
- 51 exp Cystic Fibrosis/ 36935
- 52 exp Arthritis, Rheumatoid/ or exp Rheumatology/ 123976
- 53 exp Neuromuscular Diseases/ 321561
- 54 exp Intestinal Diseases/ 659941
- 55 exp Hypersensitivity/ 358007
- 56 Chronic disease/ 270493
- 57 exp Skin Diseases/ 1069704
- 58 exp Chronic Pain/ 17627
- 59 or/29-58 [10 chronic diseases] 7488197
- 60 (classroom? or class-room?).tw,kf. 19567
- 61 (school? not (medical school? or "school of medicine" or "nursing school? of school of nursing")).tw,kf. 246265
- 62 "School-based".tw,kf. 15176
- 63 Schools/ 43312
- 64 School Health Services/ 17823
- 65 (secondary adj2 education).tw,kf. 4057
- 66 or/60-65 [Schools] 269837
- 67 Adolescent/ 2120701

68 Child/ 1774320

69 (teen\* or adolesce\* or youth).tw,kf. 389409

70 (school\* adj2 (student? or pupil?)).tw,kf. 25176

71 (("11" or "12" or "13" or "14" or "15" or "16" or "17" or "18") adj3 (year? or yr?) adj3 (old or age?)).tw. 438839

72 students/ or student dropouts/ 68102

73 or/67-72 [Adolescents] 3203822

74 Educational Status/ or Academic Success/ 55523

75 Social Participation/ 2880

76 \*"Quality of Life"/ 99353

77 (Cogniti\* or Social\* or Attendance or Academic\* or Psychosocial or psycho-social).ti. 331725

78 "Quality of life".ti. 76626

79 (view\* or attitude\* or perspectiv\* or presentee\*).ti. 273586

80 (attain\* or adaptation or absen\* or potential or achieve\* or relationship?).ti. 619940

81 exp Emotions/ 267530

82 (emotion\* or contentment or enjoy\* or impact\* or feel\* or normal\* or safe\* or behavio\* or functioning).ti. 1063789

83 (experience\* or outcome?).tw,kf. 2930401

84 or/74-83 [outcomes] 4989224

85 84 and 28 and 59 and 66 and 73 [Adolescents with 10 conditions AND outcomes AND Qualitative studies] 4017

Author (date)	Title	Country the study is based in	Relevant participant details	Data collection method	Key findings
An and Lee (2019)	Difficulty in returning to school among adolescent leukaemia survivors: A qualitative descriptive study	South Korea	14 participants 14-22 y.o. Leukaemia	Semi-structured interviews Thematic analysis	Feelings of alienation from friends Difficulty in studying Stuck being different from others Apologetic feelings for family Feelings of having an uncertain future
Bessel (2001)	Children surviving cancer: Psychosocial adjustment, quality of life, and school experiences	US	51 participants 8-17 y.o. Cancer survivors	Divided into 2 groups (8-12 y.o. and 13-17 y.o.). Mixed methods Interviews Open coding category-generating process.	Helpfulness and understanding of teachers Academic performance Peer interaction and acceptance Homebound instruction Importance of attending school
Cameron (2019)	The psychosocial interactions of Adolescent and Young Adult (AYA) cancer survivors and the possible relationship with their development	New Zealand	4 participants 16-19 y.o. + 6 participants 20-25 y.o. Cancer survivors	Face-to-face interviews + one-year follow up interview. Thematic analysis.	Personal privacy and sharing of information Independence Identify formation Positivity Acknowledgement v being treated normally Support instead of supporting others
Choquette, Rennick & Lee (2015)	Back to School After Cancer Treatment: Making Sense of the Adolescent Experience	Canada	11 participants 13-17 y.o. Cancer survivors	Face-to-face interviews. Photo-elicitation. Line-by-line, open and axial coding. Meaning-making theoretical model integrated as a guide.	Being on the right track to recovery Bridging the two worlds Establishing a new life at school
Christian, B. J.; D'Auria, J. P. (1997)	The child's eye: memories of growing up with cystic fibrosis	US	20 adolescents 12-18 y.o. Cystic Fibrosis	Retrospective interviews Life event line used. Field notes also taken. Open coding, axial coding.	Keeping secrets Hiding visible differences Discovering a new baseline
Cotter (2016)	The journey through school for children with cystic fibrosis : an interpretive phenomenological analysis	Ireland	4 participants 11-16 y.o. Cystic Fibrosis	In-depth interview IPA	Disruption to school life Being in control Reducing embarrassment Friends supporting Uncertainty Goals and the future
D'Auria, Christian, Henderson & Haynes (2000)	The company they keep: the influence of peer relationships on adjustment to cystic fibrosis during adolescence	US	15 participants 17-22 y.o. Cystic Fibrosis	Third study in a series of 3 qualitative studies. Interviews. Constant comparative method Thematising and coding	Losing ground Being out the loop Finding a new company of friends Fighting a never-ending battle

Dockett (2004)	"Everyone was really happy to see me!" The importance of friendships in the return to school of children with chronic illness	Australia	10 young people 5-16 y.o. Unspecified chronic conditions	Face-to-face interviews. Transcripts coded by 2 researchers.	Positive and negative aspects of friendships Feeling excited Feeling nervous Disclosure Difficulties in maintaining friendships
Ferguson & Walker (2014)	Getting on with life': resilience and normalcy in adolescents living with chronic illness	Australia	31 participants 10-18 y.o. Unspecified chronic conditions	Longitudinal case studies Informed by interviews of participants in 3 'waves' over 3 years (first one photo-elicitation) Thematic coding Both transcripts and materials (photos) analysed	Managing lives by focussing on opportunities Influences, optimism and the future Resistance to being seen as different The role of school and peers The interrelationship between normalcy and resilience
Fleischman K., Smothers, M.K, Christianson, H. F. & Carter, L. (2011)	Experiences of Adolescents with Type 1 Diabetes as They Transition from Middle School to High School	US	6 participants 14-15 y.o. Type 1 Diabetes	Interviews, structured Themes, then core ideas/ summaries, then cross-analysis.	Transition Identity Support Friends and peers Disclosure Self-care
Forgeron, Evans, McGrath, Stevens & Finlay (2013)	Living with difference: Challenges to friendships for adolescents with pain	Canada	16 participants 14-18y.o., Chronic pain	Interviews IPA	Rethinking the self with pain' Integrating pain into the self Understanding and sharing about chronic pain:  'Rethinking friendships' Distancing the self Needing a different quality in close friendships
Fottland (2000)	Childhood Cancer and the Interplay between Illness, Self-evaluation and Academic Experiences	Norway	8 school children 11-19 y.o. Cancer survivors	Semi-structured interview Young people interviewed individually and then parents introduced together and, lastly, hospital staff interviewed in groups. Thematic	Attainment Attendance Lack of confidence Peers Catching up on social, physical and recreational activities a challenge
Gabe, Bury & Ramsay (2002)	Living with asthma: The experiences of young people at home and at school	UK	55 participants 11-16 y.o. Asthma	Interviews Thematic analysis	Experiencing asthma Explaining asthma Management of asthma
Gathercole (2017)	The educational experiences of children with cystic fibrosis	UK	5 participants 9-17 y.o. Cystic Fibrosis	Online semi-structured interviews Option for photovoice Mixed analytical methods (thematic)	Being me first Balancing treatments and school activities Staying well at school Knowing about CF CF impacting learning Educational support Negotiating CF alongside adolescence

Glason (1995)	A descriptive and exploratory pilot study into school re-entrance for adolescents who have received treatment for cancer	UK	5 adolescents 12-16 y.o. Cancer	Semi-structured interviews. Grounded theory, exploratory and descriptive. Analysed emerging conceptual categories.	Disruption Behind in school work Normality
Holley, Walker, Knibb, Latter, Liossi, Mitchell, Radley, Roberts (2018)	Barriers and facilitators to self-management of asthma in adolescents: An interview study to inform development of a novel intervention	UK	28 participants 12-18 y.o. Asthma	Focus groups and interviews Inductive thematic analysis	Forgetting treatment Managing medication Knowledge Difficulty concentrating School staff, understanding and support at school
Holmstrom & Soderberg (2021)	The lived experiences of young people living with type 1 diabetes: A hermeneutic study	Sweden	10 participants 13-18 y.o. Type 1 Diabetes	In-depth, open-ended, qualitative interviews. Thematic analysis.	Living a transformed and re-organised everyday life Feeling new emotions in the body Living a governed everyday life Being affected as a person Being met with understanding and support Informing about diabetes is important School can be problematic
Kime (2014)	'Join us on our journey': exploring the experiences of children and young people with type 1 diabetes and their parents	England	116 participants 6-25 y.o. Type 1 Diabetes	3 year multisite study. Nine acute trusts across Yorkshire and the Humber region. Talking groups (term coined by the young people) separated by age (6-11, 12-14, 15-17, 18-25). Thematic analysis.	Diabetes care Education Communication and support School Transition
Kuntz, Anazodo, Bowden, Sender & Morgan (2019)	Paediatric Cancer Patients' Treatment Journey: Child, Adolescent, and Young Adult Cancer Narratives	US	30 participants 10-25 y.o. Leukaemia, Solid Tumours	Semi-structured interviews. Transcripts analysed in detail by each member of team. Thematic analysis. Peer evaluations.	Activity challenges Disconnection from school: Importance of storytelling Communication challenges The value of altruism towards patients in the future
Kyngas (2004)	Support network of adolescents with chronic disease: adolescents' perspective	Finland	40 participants 13-17 y.o. Asthma, Epilepsy, Juvenile Rheumatoid Arthritis, Type 1 Diabetes	Interviews dealt with 2 topics: everyday life with a chronic disease and informant's support network. Content analysis.	Peers: Fellow sufferers Friends without chronic condition School: Sometimes used condition as an excuse Comfort in nurse knowing Acceptance from peers v. teasing and causing trouble

Lakeman (2021)	The school experiences of young people with a chronic health condition : an interpretative phenomenological analysis	UK	5 participants 13-16 y.o. Type 1 Diabetes, Epilepsy, Cerebral Palsy, Mitochondrial Genetic disease	Semi-structured interviews, creative task to prepare. IPA.	Autonomy Relationships and belonging Navigating the School Day Emotional Wellbeing at School Planning for the Future
Li, Lopez, Chung, Ho & Chiu (2013)	The impact of cancer on the physical, psychological and social well-being of childhood cancer survivors	China	15 participants 8-16 y.o. Leukaemia, Lymphoma, Brain Tumour, Osteosarcomas, Kidney Tumour, Germ-cell Tumour	Semi-structured interview Content analysis Peer debriefing	For most, some impact on academic performance and pay extra efforts to keep up
Lightfoot, Wright & Sloper (1999)	Supporting pupils in mainstream school with an illness or disability: young people's views	UK	33 participants 11-16 y.o. Unspecified chronic condition, physical disability	Semi-structured interviews Framework analysis	Absence Exclusion Relationships with teachers Relationships with peers
MacMillan, Kirk, Mutrie, Moola & Robertson (2015)	Supporting Participation in Physical Education at School in Youth with Type 1 Diabetes: Perceptions of Teachers, Youth with Type 1 Diabetes, Parents and Diabetes Professionals	Scotland, UK	16 participants 7-14 y.o. Type 1 Diabetes	Interviews for young people (also focus groups with teachers, FG and int with health care professionals). Constructivist thematic analysis.	Differences between primary and secondary schools Areas requiring address in all schools What teachers can do to help accommodate youth with type 1 diabetes What schools can do to help accommodate youth with type1 diabetes
Newbould, Francis & Smith (2007)	Young people's experiences of managing asthma and diabetes at school	UK	69 participants 8-15 y.o. Asthma and Diabetes	Interviews with young people (and separate interviews with parents). . . Coding and thematising	Access to medication whilst at school Use of medication at school Impact on regimen Role of teachers and 'informed friends' Exercise School trips Being different
Pini, Gardner & Hugh-Jones (2019)	How and Why School Is Important to Teenagers with Cancer: Outcomes from a Photo-Elicitation Study	UK	12 participants 13-16 y.o. Leukaemia, Lymphoma, Soft Tissue Sarcoma or Bone Tumor	Photo-elicitation interviews 2, 6, and 9 months post-diagnosis. IPA. 9 participants completed 3 interviews, 3 completed 1.	Falling behind Controlling the story Conflicting priorities Maintaining educational pace A paused life? Finding a way to be the same but changed Legacy of missed schooling

Pini, Gardner, Hugh-Jones (2016)	How teenagers continue school after a diagnosis of cancer: experiences of young people and recommendations for practice	UK	12 participants 13-16 y.o. Leukaemia, Lymphoma, Soft Tissue Sarcoma, Bone Tumour	Longitudinal, photo-elicitation study with interviews over three time points. 1 interview in first 2 months of diagnosis, one approx 6 months post diagnosis, one at approx 9 months post diagnosis. IPA	Regulation and calibration Regulatory importance of exams and grading Belonging to the school community Damaging effect of miscommunications Changing peer dynamics and norms Adapting to altered appearances Special consideration v normality
Pini, Hugh-Jones, Shearsmith, Gardner (2019)	What are you crying for? I don't even know you' - The experiences of teenagers communicating with their peers when returning to school	UK	12 participants 13-16 y.o. Lymphoma, Hodgkin's Lymphoma, Osteosarcoma, A-plastic Anaemia or Acute Lymphoblastic Leukaemia	Photo-elicitation, interviews conducted at 3 time points during the year. Following diagnosis of lymphoma, Hodgkin's lymphoma, osteosarcoma, A-plastic anaemia, or acute lymphoblastic leukaemia. IPA.	Approaches to telling Lives becoming public property Owning the story
Ragni Cappelletti, De Stasio, Tondo, Specchio, Vigevano & Gentile (2020)	The impact of epilepsy on adolescence: a quali-quantitative investigation using focus group	Italy	8 participants 15-20 y.o. Epilepsy	Mixed methods: qualitative, focus groups quantitative, self-report questionnaire Thematic coding	Peer relationships and acceptance Autonomy School as bad place to have a seizure Lack of staff skills Concern over academic achievement Future
Secor-Turner, Scal, Garwick, Horvath & Kellerman Wells (2011)	Living With Juvenile Arthritis: Adolescents' Challenges and Experiences	US	7 participants 14-21 y.o. Juvenile Arthritis	2 Focus groups, semi-structured interview protocol. 1 x 14-21 y.o. and 1x 22-29 y.o. Descriptive content analysis	Challenges included playing sports/ participating, doing schoolwork and talking to teachers Pain impeded ability to complete some work Management of pain and exercising
Vera et al. (2015)	The lived experience of pain in adolescents diagnosed with cystic fibrosis	US	5 participants 13-19 y.o. Cystic Fibrosis	Exploratory descriptive design. Interviews exploring pain experiences within 5 domains: pain characteristics, activities, relationships, work/school life and healthcare team Content analysis with team-based constant comparisons.	Negative impact of restrictions in daily life Social life and emotional toll - missing school functions, social activities and sports Disclosure to teachers
Wakefield, Puhl, Litt & Zempsky (2020)	"If it ever really hurts, I try not to let them know:" The use of concealment as a coping strategy among adolescents with Chronic Pain	Canada	18 participants 12-17 y.o. Chronic Pain	5 focus groups of 3-5 adolescents. Directed content analysis, inductive content analysis.	Avoidance of judgement Avoidance of being a social burden Desire to be treated normally Social isolation Cognitive burden

Wilkie (2012)	"Absence Makes the Heart Grow Fonder": Students with Chronic Illness Seeking Academic Continuity through Interaction with Their Teachers at School	Australia	11 participants Year 10-12 Cancer, Anorexia Nervosa, Conversion Disorder, Renal Failure, Multiple Sclerosis and Cochlear implant complications	A qualitative collective case study of students and their teachers, involving observations, interview and questionnaire.	Teachers finding out Teacher concern Ambiguity of school and teacher responsibility
Winger et al (2013)	Sometimes it feels as if the world goes on without me': adolescents' experiences of living with chronic fatigue syndrome	Norway	18 participants 12-18 y.o. Chronic Fatigue Syndrome	In-depth interviews	Being forgotten by friends, school teachers and family members Teaching staff not understanding Reduced school attendance Feeling left behind by peers Some positive aspects
Zhu & Van Winkel (2015)	Using an ICT tool as a solution for the educational and social needs of long-term sick adolescents	Belgium	8 participants 12-19 y.o. Fibromyalgia, CVS, CRPS, Vascular problems, Hodgkin's, Operation leg extension, Depressive symptoms, Auto-immune disease	Online survey (young people) and interviews (young people and parents separately)	maintaining connection with school Peers and social contact School community

Author / Date	Title	Was there a clear statement of the aims of the research?	Is a qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research?	Was the recruitment strategy appropriate to the aims of the research?	Was the data collected in a way that addressed the research issue?	Has the relationship between researcher and participants been adequately considered?	Have ethical issues been taken into consideration?	Was the data analysis sufficiently rigorous?	Is there a clear statement of findings?	How valuable is the research?
An 2019	Difficulty in returning to school among adolescent leukemia survivors: A qualitative descriptive study	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes
Bessell 2001	Children surviving cancer: Psychosocial adjustment, quality of life, and school experiences	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes
Cameron 2019	The psychosocial interactions of Adolescent and Young Adult (AYA) cancer survivors and the possible relationship with their development	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Christian 1997	The child's eye: memories of growing up with cystic fibrosis	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes
Cotter 2016	The journey through school for children with cystic fibrosis : an interpretive phenomenological analysis	Yes	Yes	Yes	Yes	Yes	Unsure	Yes	Yes	Unsure	Yes

D'Auria 2000	The company they keep: the influence of peer relationships on adjustment to cystic fibrosis during adolescence	Yes	Yes	Yes	Unsure	Yes	No	Yes	Yes	Yes	Yes
Dockett 2004	"Everyone was really happy to see me!" The importance of friendships in the return to school of children with chronic illness	Unsure	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes
Ferguson 2014	'Getting on with life': resilience and normalcy in adolescents living with chronic illness	Yes	Yes	Yes	Unsure	Yes	No	No	Yes	Yes	Yes
Fleischman 2011	Experiences of Adolescents with Type 1 Diabetes as They Transition from Middle School to High School	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes
Forgeron 2013	Living with difference: Challenges to friendships for adolescents with pain	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Fottland 2000	Childhood Cancer and the Interplay between Illness, Self-evaluation and Academic Experiences	Yes	Yes	Yes	Unsure	Yes	No	No	Yes	Unsure	Yes

Gabe 2002	Living with asthma: The experiences of young people at home and at school	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Unsure	Yes
Gathercole 2017	The educational experiences of children with cystic fibrosis	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Glasson 1995	A descriptive and exploratory pilot study into school re-entrance for adolescents who have received treatment for cancer	Yes	Yes	Yes	Unsure	Yes	No	Yes	Yes	Unsure	Yes
Holley 2018	Barriers and facilitators to self-management of asthma in adolescents: An interview study to inform development of a novel intervention	Yes	Yes	Yes	Yes	Yes	Unsure	Yes	Yes	Yes	Yes
Holmstrom 2021	The lived experiences of young people living with type 1 diabetes: A hermeneutic study	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Kime 2014	“Join us on our journey”: exploring the experiences of children and young people with type 1 diabetes and their parents	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Unsure	Yes

Kuntz 2019	Pediatric Cancer Patients' Treatment Journey: Child, Adolescent, and Young Adult Cancer Narratives	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Kyngas 2004	Support network of adolescents with chronic disease: adolescents' perspective	Yes	Yes	Yes	Unsure	Yes	No	Yes	Yes	Yes	Yes
Lakeman 2021	The school experiences of young people with a chronic health condition : an interpretative phenomenological analysis	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Li 2013	The impact of cancer on the physical, psychological and social well-being of childhood cancer survivors	Yes	Yes	Yes	Unsure	Yes	No	Yes	Yes	Yes	Yes
Lightfoot 1999	Supporting pupils in mainstream school with an illness or disability: young people's views	No	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes
MacMillan 2015	Supporting Participation in Physical Education at School in Youth with Type 1 Diabetes: Perceptions of Teachers, Youth with Type 1 Diabetes, Parents	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

	and Diabetes Professionals											
Newbould 2007	Young people's experiences of managing asthma and diabetes at school	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes
Pini 2016	How teenagers continue school after a diagnosis of cancer: experiences of young people and recommendations for practice	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes
Pini 2019	'What are you crying for? I don't even know you' - The experiences of teenagers communicating with their peers when returning to school	Yes	Yes	Yes	Yes	Yes	Unsure	Yes	Yes	Yes	Yes	Yes
Pini 2019	How and Why School Is Important to Teenagers with Cancer: Outcomes from a Photo-Elicitation Study	Unsure	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Ragni 2020	The impact of epilepsy on adolescence: a quali-quantitative	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes

	investigation using focus group											
Rennick&Lee 2015	Back to School After Cancer Treatment: Making Sense of the Adolescent Experience	Yes	Yes	Yes	Yes	Yes	Unsure	Yes	Yes	Yes	Yes	Yes
Secor-Turner 2011	Living With Juvenile Arthritis: Adolescents' Challenges and Experiences	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Vera 2015	The lived experience of pain in adolescents diagnosed with cystic fibrosis	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Wakefield 2021	"If it ever really hurts, I try not to let them know:" The use of concealment as a coping strategy among adolescents with Chronic Pain	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Wilkie 2012	"Absence Makes the Heart Grow Fonder": Students with Chronic Illness Seeking Academic Continuity through Interaction with Their Teachers at School	Yes	Yes	Yes	Yes	Yes	No	Unsure	Yes	Yes	Yes	Yes

Winger 2014	'Sometimes it feels as if the world goes on without me': adolescents' experiences of living with chronic fatigue syndrome	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Zhu 2015	Using an ICT tool as a solution for the educational and social needs of long-term sick adolescents	Yes	Yes	Unsure	Yes	Yes	No	Unsure	Unsure	Yes	Yes

	Keeping up / catching up / missing out / looking forward	Identity	Relationships with peers	Normality and difference	Autonomy	Relationships with staff
An & Lee 2019	✓	✓	✓	✓		
Bessel 2001	✓		✓	✓	✓	✓
Cameron 2019	✓	✓	✓	✓	✓	
Choquette, Rennick & Lee 2015	✓	✓	✓	✓	✓	✓
Christian & D'Auria 1997	✓	✓	✓	✓	✓	
Cotter 2016	✓	✓	✓	✓		✓
D'Auria, Christian, Henderson & Haynes 2000	✓	✓	✓		✓	
Dockett 2004	✓	✓	✓	✓		✓
Ferguson & Walker 2014	✓		✓	✓		
Fleischman et al. 2011	✓		✓	✓	✓	✓
Forgeron et al. 2013	✓	✓	✓	✓	✓	✓
Fottland 2000	✓	✓	✓	✓	✓	✓
Gabe, Bury & Ramsay 2002	✓		✓	✓	✓	✓
Gathercole 2017	✓				✓	✓
Glasson 1995	✓	✓	✓		✓	✓
Holley et al. 2018	✓		✓			✓
Holmstrom & Soderberg 2021	✓	✓	✓	✓	✓	✓
Kime 2014	✓		✓	✓	✓	✓
Kuntz et al. 2019	✓		✓			
Kyngas 2004	✓		✓		✓	✓
Lakeman 2021	✓		✓	✓	✓	✓
Li et al. 2013		✓	✓	✓	✓	
Lightfoot, Wright & Sloper 1999	✓	✓	✓	✓	✓	✓
MacMillan et al. 2015	✓	✓	✓	✓	✓	✓
Newbould, Francis & Smith 2007		✓	✓	✓	✓	
Pini, Gardner & Hugh-Jones 2016	✓	✓	✓	✓	✓	
Pini, Gardner & Hugh-Jones 2019		✓	✓	✓	✓	✓
Pini, Hugh-Jones, Shearsmith & Gardner 2019	✓		✓		✓	✓
Ragni et al. 2020	✓	✓	✓	✓	✓	
Secor-Turner et al. 2011	✓		✓			✓
Vera et al. 2015			✓	✓		✓
Wakefield, Zempsky, Puhl & Litt 2021	✓					✓
Wilkie 2012	✓	✓	✓			✓
Winger, Ekstedt, Wyller & Helseth 2014	✓		✓			✓
Zhu & Van Winkel 2014	✓		✓	✓	✓	

	Keeping up / catching up / missing out / looking forward	Identity	Relationships with peers	Normality and difference	Autonomy	Relationships with staff
An & Lee 2019	"I want to be a nurse, doctor, or a teacher, but I cannot be them all, because my school grades need to be very good for it" p.74	"I was very conscious of people, I thought people were looking at me, even though they weren't..." p.73	"When I didn't go to school and would meet up with my friends, should I say that we didn't have much to discuss, when they talked about things that I didn't know about, I felt a little alienated..." p.72	"...when my class was being punished, I got many exceptions. I was worried that if teachers treat me that way even though I could do those things too and it was okay, my friends would not like it" (15 y.o. p.73)		
Bessel 2001	"I keep quiet and don't ask a lot of questions." "I keep a low profile so the teacher thinks I understand." "I do just enough to get by so I can stay with my friends." P.354		"the ones that stick around even when you're sick" ... "thought I had a disease they could catch or that I had AIDS" (p.354)			"especially sensitive," "caring," and "like a grandmother" "She always found a way to make me feelgood and didn't treat me like I would break" p.352
Christian & D'Auria 1997				"When I do sports and things, I can look normal, but I have to try twice as hard to do it" ... "and so when I play baseball next time, I'm not going to tell my coach I have it. So he won't treat me any different than the other kids" p.7  "., they're normal, because you can't define		

				what normal is because they're an alternate different definition of normal, but they're normal .." p.9		
Cotter 2016	<p>"When I ... get sick ... I can miss a lot of time off school, then ... I'm trying to catch up ... in second year ... I missed so much school and in transition year ... I was in hospital as well so I missed so much school then too"</p> <p>"I've no problems with getting to classes ... If I had a problem I'd ask a teacher and they'd help out ... if I miss school ... there's teachers in the hospital that I talk to ... I ... try catch up on notes from ... the [local] teachers ... so it's grand"</p>	<p>'It's just the way I am. Like I don't act as if there's something wrong ... as if I've a big problem. I just don't see the point in that. I'm just acting myself and act normal as if I don't have it. Like it doesn't affect me that way that I have to act, I feel like I have to act a certain way or act different because I have CF and they don't'</p>	<p>"my friends are so good like ... if there's something wrong they'll come down to me, they'll stay with me ... after school ... they'll make sure I'm okay" (P2, 9)</p>	<p>"See, I don't want [the local] teachers to treat me differently because I'm sick" (P1, 22)</p> <p>"I suppose ... they just think I'm normal really. Luckily ... I don't want to be treated differently. I just want to be treated the same" (P4, 9)</p> <p>"I don't think they see me as anything different. I think they just see me as what I am."</p>		<p>"If I had a problem I'd ask a teacher and they'd help out" (P1, 20)</p>
D'Auria, Christian, Henderson & Haynes 2000	<p>"I never got to know people as well as I would have if I hadn't missed so much school."</p>		<p>"She [best friend] still asks questions. She still doesn't understand it and I've known her 12years. You can never</p>		<p>"It's something you're going to have to try and take care of. You're going to have medicines to take every day, every</p>	

	<p>"I'm not at school as much as some of the others, so you're kind of out of the loop when you come back after 3 weeks. Who's seeing who, you know. That can change radically in 3 weeks"</p>		<p>completely know somebody until you are someone with CF."</p>		<p>time you eat.... There will be times when you are sicker than others. There will be times when you don't feel good but you're not sick, and that's when you have to push yourself. That's when you got to go and make yourself do something!" p.180</p>	
<p>Ferguson &amp; Walker 2014</p>	<p>"... I really started missing my life because you know being in hospital and sort of you have a boundary. Yeah I started missing my friends and my school and my life at that point." (p.236)</p> <p>"Well it was hard, it was really hard at the start [of the year] because like I just didn't want to be there [at school] because it was too hard like to get up out of bed and go there"</p> <p>"you get back to school and you're</p>			<p>"Yeah I guess the fact that I can still do, let's say most normal things that people my age do and yeah I guess that's sort of a milestone" (p.238)</p>		<p>"I had a teacher, our science teacher actually, she had a sort of like a class about what my illness was about so she told my class-mates with pictures and diagrams and that kind of thing, just a whole lesson about what Acute Myeloid Leukaemia was and what was happening to me and that kind of thing so that was, yeah I thought that was nice." P.237</p>

	really behind and you have to try and catch up and everything””					
Fleischman et al. 2011 (No quotes)						
Forgeron et al. 2013	“I studied like, every night. I study for my exams for a month in advance, I tried so hard. I passed all my courses, but not with the marks that I wanted. I think if I didn’t have the pain, I would have definitely had way higher marks than that.” E118	“It’s like an invisible enemy that no one really sees”	<p>“they just don’t understand it or want to understand it, they don’t care or something, they’re just mean.” (p.118)</p> <p>“Well those kids, they let me die an emotionally social death, they just skewered me. None of them talk to me, and it’s still like, it irks me and it’s very painful...”</p> <p>“So we were very, very close, and then I was completely alienated.” (p.120)</p> <p>“you can tell that people are kind of like, uneasy around it or they don’t fully understand. They want to ask, but they don’t, and sometimes I’ll sort of bring it up to answer their</p>	“I think I’d like them to react as normal as they could, even if I couldn’t do certain things or go certain places. I’d want them to act the same way.” E121		“This one teacher calls me the elevator mafia. And it doesn’t matter how many times I talk to him or that the guidance counselor talks to him, like he thinks he’s being funny and like that’s great and wonderful, but you have to be able to differentiate funny from mean. Like I don’t want to hear it.” E118

			questions. But it always kind of seems like a downer, and it's always about the pain." E117			
Fottland 2000	"I got a little spoiled, perhaps, I got to do whatever I wanted to, more or less, see, so I was dumb enough to use that quite a few times. Sure, I did some homework, like, but I got off easier than the others, y'know." P.263		"I'm always a bit afraid of how the others will react to what I say and do" p.263	"I didn't want to be different at school. That's why I didn't want any special aids, either, see... I didn't want any special assistance either, because I don't want to be worse than the others. When they don't need help, then I don't need help. I wanted to do everything the same as the others" p.267		
Gabe, Bury & Ramsay 2002	"You feel frustrated when you see this bunch of twenty people running off ahead and you think "Why can't I do that?" It would be nice to catch up with them once, but no." (p.1624)		"Yes, I am used to it now. I have been sent out of classes, I have been sent out of an exam because I have been annoying people." (p.1629)	"I just make myself do it, to show them just because I have got asthma I am no different"	"I have two or three of them. I keep one in my schoolbag and one at home." (l.46)	
Gathercole 2017	"Erm, it doesn't really affect me that much...not really. I do everything I want to do"  "So, it never stopped me doing anything I		"sometimes I'm bothered (about doing treatment) because it means I don't get to see my friends. But then the other way, I know it's going to help	"I want to be seen as normal. I'm a normal person" p.106	"Sometimes if I need to go to the toilet and it's like...at my high school they don't let you go to the toilet during lessons" p.119	"she had to come in and like speak to a load of my teachers and staff that I had it. So that helped a lot."  "School should probably know more

	really wanted to do” p.108  “They could like send work when you ask for it so you don’t fall behind” p.135		me with my health” p.149			about it (CF) and what it does” p.127
Glasson 1995	“didn’t know where to begin” “didn’t know how to catch-up” p.776	“lost my hair” “wore a wig” “felt like a wally” “just didn’t feel right” p.776	"friends were brilliant" "helped me back into it" "there if I needed them". (p.756)  “learnt who my real friends were” p.776			
Holley et al. 2018						“It helps when the teachers know and they do trust you that you are late to class because I had to stop to take my inhaler”p.950
Kime 2014					"I was invited to a carb-counting class to help me understand how to read labels and be confident with carb-counting. This class was really helpful" (p.26)	"Teachers complain about me having to have snacks and have drinks and go to the toilet" (p.27)
Kuntz et al. 2019	“I write a journal on my computer and keep track of the daily ‘every-thing’ that happens. I have been doing this for the past month. I want to look at it in the end and see just					

	what I went through. In the future, I want to go to medical school, so I can look back on this experience to help me for in my essay" p.45					
Kyngas 2004			"some classmates always support me, even though some others tease me, for example, because I have to take my medication. The supporters remind me of how important it is to take my medication and also tell the teasers that they do not understand the importance of medication" (p.291)			"...it is safe to know that if I got such bad hypoglycemia that I cannot help myself, the school nurse will know what to do..."
Lakeman 2021	"I can't really concentrate" "I missed a lot of time" "Going to try to (-- not involve T1D in my future" "when I go to uni the big worry is around making sure that I've got the right support and the right accessibility"	(lots from author but not many direct quotes to support this)	"they push me towards to being friends more with disabled people" "I couldn't sit with my friends at lunch"	"...don't want to be treated differently to everyone else but sometimes I need to be treated differently"	"They feel that I can't manage it myself" "My management was fine. There wasn't an issue. At all. But all of a sudden, she* made me miss a lesson which I liked. She* made me miss my break and this happens a lot." (Line 261) *she= school nurse	"None of the teachers are really helpful" "I mean I've got a teacher at the moment who is also a diabetic too so if I am in her class and my pump stops or something, she'll know that I've got to do stuff and

	“it’s quite hard to catch up with work as there is quite a lot, a lot to do at home”					she doesn’t mind.” (Line 259-261)
Lightfoot, Wright & Sloper 1999	“I miss enough of it when I’m really poorly and I just enjoy it when I’m there. So if I’ve got a bit of a headache I don’t tell anybody...I have offdays but I don’t really want to come home” p.272 Some of the teachers, if I asked them to explain it they would just say it’s your own fault for not being here and I’d say `well it ain’t my fault’...I would like more help with the work.” P.273		“I get picked on, pick, pick, pick, pick, pick, and I get called the horriblest names and when I go off crying people go and tell (the deputy head), she doesn’t do anything at all. I can’t really do anything” p.277			“teachers couldn’t understand that, they just thought I was not bothering or sometimes they didn’t try and explain the work to me and they’d say `Oh, you know what you are doing””p.273  was upset because I thought, well, all the teachers know, but they don’t seem to care... I said `I can’t do this and if you make me do it I’ll be seriously poorly’. But they still made me do it.” P.274  “The more people who know the less mistakes are made...ignorance is the root of all the problems I’ve had, it’s people with a lack of knowledge that have made it difficult” p.275

Li et al. 2013	<p>"I find difficulty in paying attention to what I am doing. In the past, I could study 6 h per day. After recovery, I am easily distracted by other things. I could hardly concentrate on my study."p.217</p> <p>"I was a member of a football team at school. Now, I am no longer able to join the team because of the decrease in physical strength and endurance." "The impact cancer had on me was on the learning side. I had to make extra efforts in order to catch up with my studies after my remission." P.217</p>		<p>"After remission, I feel the age gap between my classmates. The main reason is that I haven't hung out with them for a long time. We cannot understand each other as we have different growing experience."p.217</p>			
MacMillan et al. 2015 (very few YP quotes)						<p>"I do tell them [teachers] but they don't actually realise, if I'm actually going to be low but I do tell them...Once eh, eh I</p>

						had my lunch, I was low before it. Had my lunch, they test me after it, I was...well high, of course that was supposed to happen...They didn't know that. So then they had to make me run about and that...affect[ed] me to go low again...I don't think they realised how high it could go." (p.11)
Newbould, Francis & Smith 2007					"We are meant to put our hand up and ask Miss for our blue(inhaler) but then I'd have to walk all the way to the office to get it. So my Mum she said to me just to keep it in my pocket or my pencil case and just use it when I need it."p.1079	"... my friends said Mr Simms was just sort of staring and he didn't move" (p.1079) "but Mum went to the school and Mrs White also came to our house and she taught her all about what I need and what to do when I go high and low and stuff"p.1080
Cameron 2019		"the girl with cancer" "they might still think of me as the	"I lose quite a lot of friends because they'd say they were my friends and then	"...they still treated me like I was the same person and, just being treated like I was.. like		

		person with cancer but I'd like to think that I've kind of broken away from that now, and I'm now just me... Lisa 2.0.You know? Lisa post - cancer" p.62	they'd just talk about me behind my back, or be too scared to talk to me"p.65	I wasn't any different... was really helpful for me." P.65		
Pini, Gardner & Hugh-Jones 2016	"Because if they look back on that and then saw that [bad report] and not knowing what had gone on that year thinking in year 9 'oh she messed about, she got messy, she was predicted an F and now a U in history' it wouldn't have been very fair on me."	"...people obviously are going to say 'oh I wonder if she's got a wig on' because everybody would do that, I'd do that, just wonder." "sometimes I can just dump my crutches down and I'll walk, so then I think people are like, 'what an attention seeker!' kind of thing."	"I just needed her there! To be able to give me that confidence, because she's in a lot of my lessons as well so she's just. she's the strong one really!"	"I wanted them to not be exactly the same with me, I wanted them to sort of. sort of be responsible, normally they're quite crazy and weird. Like not feel sorry for me or anything but be more thoughtful but still be their normal selves."	"It was quite, not annoying but, I don't know, you just kind of wanted to be left alone sometimes and they were always asking, I don't know, like yeah, always like making sure you're okay, which is a good thing but it just, after a while it kind of gets a bit, I don't know, like the everyday thing."	"Well the sheet that I've been given has always got a contact list on. Which doesn't really mean that they're very helpful, it just means that they've got in contact!"

Pini, Gardner & Hugh-Jones 2019	"I think maybe like the concentration side of things. I'm a bit nervous about that actually, sort of sitting in a classroom listening for, working. I think it could be quite, not difficult, but a challenge" (p.13)	"why are you crying? It's not you, it's my hair, I'm not bothered, it's just hair" (p.12) "That point was like, that was a good point for me because I had the confidence to actually go to school without my wig on." 12	"They [ healthy peers] don't know what it's like and they don't know what pain you go through" (p.8)	"just want to been seen as me being normal" p.11	"get my body how I want it to be" "forget it [cancer]"	
Pini, Hugh-Jones, Shearsmith & Gardner 2019			"they all just asked, everybody asked me, what's that, what is it and I didn't know so I just said, I don't know but everybody asked me it, virtually everybody and it just got really irritating and annoying, you know" "So... yeah that first day back... people that I didn't even talk to normally they just started crying, and it was like 'what are you crying for? I		"So telling them I'd just say... I wouldn't tell them in front of everybody else, I'd tell them sort of like two or three people at a time and things and just say 'look I've got cancer and I will tell you everything that I could' and they were like 'oh right... are you going to beat it?', 'yeah, of course I am! What do you think?!"	

			don't even know you"			
Choquette, Rennick & Lee 2015	"During my treatment, I didn't talk to anyone from school. No one. School was, like, gone. Like it was another world. Like the hospital was the new school, like my second world" (p.6)	"When I look at myself in the mirror, it's like I do not recognize myself."	"I didn't know if [my friends] were gonna react like, 'oh, that guy had cancer, I don't want to get it.' They probably didn't know it was not contagious..." (p.4) "Just walking around the halls and everyone just staring at you, not talking, just feeling like [crap]. You know, everyday, I did not want to, like, go to school." (p.4) "struggle to rebuild friendships"	'You feel like you're special, you're different. It's like you're someone else, not like everyone around you, 'cause you need more extra care or, like, attention so it didn't feel right."	"I want to do this by myself, you know. It's my battle... I want to take this one for myself, but always she asked."	
Holmstrom & Soderberg 2021		"It felt like I was regarded as a completely different person in school almost like as I was a disease..."		"It felt like I was regarded as a completely different person in school almost like as I was a disease." (p.6)	" do not feel safe at school.... I'm not sure people would notice if I got a hypo...." (p.6) – autonomy because reliant on self-management?	"It was strange that no one cared... it was like no one was responsible and no one cared and the headmaster thought it was so much fuss with me and told Mum not to enlarge problems." (p.7)

						“At first, Mum was in school with me and then she came to school for lunch and helped me with the insulin. Then Mum taught the teachers how to help me manage with blood sugar and all”
Secor-Turner et al. 2011	I play football there. And for me, I can't play in all the games. I have to like go in a couple plays, sit out a couple plays, take my medicine. And they like, why you just not stayin' in?. Because I have to do this so I could go in for the next round or do something else. Cause if I don't do this, then my bones start achin', swell up, and I'm in the hospital. So I'd rather take my medicine and sit		'Having your friends understand what you're going through.' (= a challenge)			"like I did really bad in the sit-n-reach last year. And my teacher got really mad at me and then she told me that I needed an attitude adjustment, cause I was saying that I was sore whenever I was in gym or whatever. She was yelling at me and that was before I knew that I had arthritis. And then we told her about it, and she's like, oh, whatever." (p.305)

	out a couple plays than go straight to the hospital" (p.305)					
Dockett 2004			They [peers at school] worry about these teeny little things ...I don't see them outside school...At school I just don't link up with any of the kids at school. I don't feel as if I'm a part ...I am just there." (p.31)  "It's personal. I only tell it to friends."p.30 (also autonomy?)		"It's personal. I only tell it to friends." (also peers?)  "I didn't really have the friends I have now back then ... I think they [previous friends] were too scared. They didn't know whether I would cry. They were scared to come near me because they didn't know whether I was sick." P.30	
Vera et al. 2015	"I usually have tests like every other day... and I remember, 'Oh wait, I'm going to have to catch up on everything' and I'm like 'Blergh!'"		"Most of my friends, like, they understand."			
Wakefield, Zempsky, Puhl & Litt 2020			"In my school I don't have like any friends and like if I did, they probably wouldn't	"when you have a 504 plan [school accommodations], sometimes you kind		"I wouldn't tell [my teachers] I'm having a whole bunch of pain... I would get on

			like if they probably want do a lot of stuff but like I can't like I can't go to the movies all the time because I can't walk around:::like then I would feel upset because like every day I come home and cry my eyes out because I have no friends."	off or get about what you have, or you try to ignore it, because you want to be as normal as possible and fit in with everybody, so you don't want to bring it up"  "you don't want to be treated like, kind of like, not like you're a patient, but you want to be treated as if you're like just regular."		the bad side of some teachers"
Wilkie 2012	I don't — I'm not good getting 'A + 's but I just want it to be a pass. That's all I want it to be.					"Keep in touch regularly"  "Just to try and stay in contact with them as much as you can, because they need to have their teacher there."  "I think just to, like don't pressure them but just stay in contact and, like I've found with all my

						teachers, they never, they just gave me the work and said if you're up to it, do it. There was never any pressure and that sort of helped."
Winger, Ekstedt, Wyller & Helseth 2014	"..actually I was only present at school, sitting on my chair in the classroom. Did nothing. Waiting to go home.." "No, then [in the future], I'm well, then I can do everything. Then I'm gonna catch up!"	"...I kind of separate between what I want and what my body wants, and so in a way I manage to distinguish between myself and my disease quite well"				
Zhu & Van Winkel 2014 (Most quotes about ICT tool)			"now my classmates saw me much more often, they trusted me more as they saw I was working hard" p.241			
Ragni et al. 2020	"I'm afraid not to find my place in the world, not to find a job"		"They distance themselves from you because you are different. Differences scare [people], it's a form	"They distance themselves from you because you are different. Differences scare [people], it's a	"Epilepsy is big trouble! Even at school, I can't go to the bathroom alone, somebody's got to come with me! I'm	

			of discrimination" (p.9)	form of discrimination" (p.9)  "They push you away because you are different."	forced to go to the toilet with the anxious thought that there is someone else there with me!"	
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