REVIEW

Family reported outcomes, an unmet need in the management of a patient’s disease: appraisal of the literature

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Abstract

Background: A person’s chronic health condition or disability can have a huge impact on the quality of life (QoL) of the whole family, but this important impact is often ignored. This literature review aims to understand the impact of patients’ disease on family members across all medical specialities, and appraise existing generic and disease-specific family quality of life (QoL) measures.

Methods: The databases Medline, EMBASE, CINHAL, ASSIA, PsycINFO and Scopus were searched for original articles in English measuring the impact of health conditions on patients’ family members/partner using a valid instrument.

Results: Of 114 articles screened, 86 met the inclusion criteria. They explored the impact of a relative’s disease on 14,661 family members, mostly ‘parents’ or ‘mothers’, using 50 different instruments across 18 specialities including neurology, oncology and dermatology, in 33 countries including the USA, China and Australia. These studies revealed a huge impact of patients’ illness on family members. An appraisal of family QoL instruments identified 48 instruments, 42 disease/speciality specific and six generic measures. Five of the six generics are aimed at carers of children, people with disability or restricted to chronic disease. The only generic instrument that measures the impact of any condition on family members across all specialities is the Family Reported Outcome Measure (FROM-16). Although most instruments demonstrated good reliability and validity, only 11 reported responsiveness and only one reported the minimal clinically important difference.

Conclusions: Family members’ QoL is greatly impacted by a relative’s condition. To support family members, there is a need for a generic tool that offers flexibility and brevity for use in clinical settings across all areas of medicine. FROM-16 could be the tool of choice, provided its robustness is demonstrated with further validation of its psychometric properties.

Keyword: Family member, Partner, Impact of illness, Quality of life, Family quality of life, FROM-16, Unmet need, Management of a patient’s disease

Background

A person’s chronic health condition or disability can have a huge impact on the quality of life (QoL) of the whole family. Sometimes this impact may be similar to or even greater than that experienced by the patient [1–3]. Although awareness of the impact of a person’s disease on family quality of life (FQoL) has recently been increasing, there is a need to measure this impact in the clinical setting to inform those providing support to the family. Turnbull et al. first proposed the term in 2000 and defined normal “family quality of life” as being “where the family’s needs are met, and family members enjoy their...
life together as a family and have the chance to do things which are important to them” [4].

Golics et al.’s [5] detailed literature review of the impact of chronic disease on a patient’s family revealed that various aspects of family life are affected by relative’s health condition. That review only identified information about a few disease areas and specialities [5] and concluded that there was no generic instrument at that time to measure disease impact on family members of patients.

The investigation of FQoL is a newly emerging field, with research now extending to many different areas of medicine. It is, therefore, timely to update the existing knowledge base on the family impact of disease and identify the development of new generic and disease-specific FQoL tools. This critical appraisal of the literature builds on the areas covered by Golics et al. [5] and summarises the greatly increased research activity over the last seven years. It aims to identify the impact of chronic disease on family members of patients across a range of medical specialities and appraise the characteristics and measurement properties of existing generic and disease-specific FQoL measures.

The definition of ‘family’ has changed over time and its use is no longer restricted to describing ‘two parents and their children living under the same roof’. In this review, we use the term as defined by Poston et al. [6] as “People who think of themselves as part of the family, whether related by blood or marriage or not and who support and care for each other on a regular basis.” This review studies the impact of a patient’s disease on all family members, including partners, whether or not they are also carers. Although the terms family caregivers, carers and informal caregivers are often used interchangeably, the only caregivers covered by this review are those unpaid carers (caregivers) who are family members or partners.

**Methods**

**Search strategy**

A search strategy was developed to identify studies published up to January 2020 that reported the impact of chronic disease on patients’ family members and partners. Six electronic databases were searched: Medline via OVIDSP; EMBASE via OVIDSP; CINHAL via EBSCO; ASSIA via ProQuest; PsycINFO Via OVIDSP; and Scopus using the PICO framework (Population: family members of chronic patients, Intervention: Patients chronic illness, Comparison: Non-applicable, Outcome: impact on family members) to identify and record the data (Additional file 1: Table S1a and S1b). The PICO framework was developed by the lead author and agreed by the other authors. The reference lists of included articles were also examined to ensure that all relevant articles were captured.

The search to identify existing generic and disease-specific FQoL measures was extended by combining search terms such as ‘family*or caregiver’ and ‘quality of life’ with the terms scale, index, measure, instrument, assessment, surveys, questionnaires, inventory, tools, generic or disease-specific (Additional file 1: Table S2). In addition, hand searches were carried out of the COnsensus-based Standards for the selection of health Measurement Instruments (COSMIN) [7] database and the reference lists of relevant articles. Google Scholar was searched for articles reporting development or psychometric properties of the instruments identified.

**Eligibility criteria**

Articles were included in the review if the source was an original paper, in the English language and measuring the impact of chronic illness or disability on patients’ family members/partner using a valid tool. Studies were excluded if they were book chapters, congress abstracts, if they used qualitative methodology or if the caregiver was not a family member. This review paper is in two parts, the first part focuses on the impact of a patient’s disease on family members and the second part appraises the instruments available to measure this impact. As one of the inclusion criteria for the second part was only to include quantitative techniques, it was felt methodologically appropriate to align the two parts by including only quantitative studies in the first part. We recognize this could be considered as a limitation of the study.

**Screening**

In the first stage of article screening, duplicates were removed, and irrelevant titles and abstracts were discarded based on eligibility criteria. In the second stage, full-text articles of potentially relevant abstracts were read and assessed against eligibility criteria by RS to make a final decision about study selection agreed by MSS and AYF.

**Data extraction**

Data extraction was carried out by RS and was discussed using an iterative process with other members of the research team (MSS and AYF). The data extracted included authors, publication year, country of study, study design, sample size, patients’ chronic disease, family member gender, relationship to the patient, impact on the family members and tools used to measure this impact (Additional file 1: Table S3).

A separate data extraction table was used for recording psychometric properties of identified family QoL instruments.
Synthesis of data
We used a thematic approach to synthesise findings. Selected papers were carefully read by RS: in case of ambiguity, papers were discussed with FMA, AYF and MSS to ensure accuracy of data extraction. The data on the impact of patients’ disease on family members were summarised as short notes for the 86 studies. These notes were then coded to capture their essence and finally, codes were sorted into potential themes.

Quality assessment and risk of bias
The quality of selected papers and assessment of risk of bias was evaluated using the Joanna Briggs quality assessment tool for cross-sectional and cohort studies, with the involvement of MSS and AYF [8]. The checklist consists of 8–11 questions with answers “yes”, “no” and “unclear”. When all answers were “yes”, the study was considered to have less chance of bias and if any answer was “no” the study was classified as having a risk of bias. Overall, all studies were moderate to high quality (Additional file 1: Table S6).

Results
Screening
A total of 7,767 articles were identified. After removing duplicates and irrelevant titles, 558 abstracts were screened. The resultant 114 articles underwent full-text review, 86 articles met all inclusion criteria and were included in the final analysis (Fig. 1).

Study characteristics
Eighty-one studies were cross-sectional, and five studies were longitudinal prospective cohort studies with follow-up ranging from one month to two years. The studies explored the impact of a relative’s disease on a total of 14,661 family members, mostly ‘parents’ or ‘mothers’, using 50 different tools across 18 specialities including neurology, oncology and dermatology and covering 33 countries including the USA, China, and Australia (Figs. 2 and 3; Additional file 1: Table S4 and S5). The most widely used tool to measure the impact of a patient’s disease on a family member was the Zarit Caregiver Burden Scale (13 studies) followed by WHOQOL (11), SF-36 (11), SF-12 (nine), IOF (seven) and EQ-5D (six) (Fig. 2). While most of the articles reported the impact of a single chronic disease on family members, ten studies included more than one chronic condition, allowing comparison of the family impact of different diseases.

Quality assessment and risk of bias
Thirteen cross-sectional studies and one cohort study did not mention confounders and strategies to address them while one cohort study did not mention reasons for loss of follow-ups. However, the remaining requirements were met for all of these studies, which all fulfilled the minimum criteria for quality. None of the 86 studies was rejected based on their quality or risk of bias. Overall, all studies were moderate to high quality (Additional file 1: Table S6).

Synthesis of findings—key impact areas
This review revealed a huge impact of patients’ illness on family members’ QoL [10–18]. In general, relatives’ chronic diseases impacted family members in similar ways, with some conditions such as cancer having a bigger impact than others. Some common themes identified in this review are discussed below.

Emotional and psychological impact
Caring for a relative’s chronic disease affects family members’ lives in many ways, impacting their emotional and psychological wellbeing [19]. The family members caring for their relative with a chronic disease were at risk of themselves developing a mental health condition, with an adult offspring or spouse at higher risk than other family members [10, 20, 21], and suffered similar psychological distress, depression and anxiety levels to that of the patient [22–24]. The presence of anxiety and/or depression in the family member was the most consistent factor influencing family members’ burden and perceived health-related QoL (HRQoL) [25, 26].

Nature of relationship and psychological impact
Mothers of children with chronic disease experienced high rates of stress, anxiety and depression [15, 27–30]. Parenting stress was higher when a child was of preschool age [31, 32] and displaying disruptive behaviours and developmental disabilities [33] or showing flares due to increased severity of their condition [34, 35]. Some parents perceived the increased caring demands of a sick child as ‘intrusive’ which led to higher levels of parental stress and psychological distress [36] affecting the perception of burden experienced by the mother [37]. However, this emotional distress did not result in mothers being less caring of the sick child [38]. The children of mothers with a chronic condition experienced more symptoms of hyperactivity and inattention, especially when the mothers had psychological problems [39]. Siblings of children with a more severe chronic condition and an unpredictable prognosis reported more internalising of problems and behavioural difficulties than siblings of children with a chronic condition that followed
a daily routine treatment pattern [40]. However, poor emotional health of siblings of children with controlled asthma was not related to disease severity [41]. Moreover, what is worrying is that parents are sometimes unaware of the impact of their child’s disease on their other children [42].

**Gender differences**
Female family members, spouses and mothers, experienced significantly higher rates of depression and anxiety than male family members [15, 21, 25, 28, 29, 43] and the impact was greater when patients suffered from a severe disease such as a long-term mental health condition [44]. However, two studies showed fathers experiencing more stress [45] and lower HRQoL [46] than mothers. Such paternal outcomes could be explained based on increased stressors arising from disease flares, such as additional medical visits and medical bills, both of which could be particularly distressing for fathers compared to mothers [46]. The reverse gender difference was found in siblings of a patient, with female siblings experiencing a lower QoL than male siblings [40].

**Impact on physical health**
Caring for a relative with a chronic disease can have an impact on family members’ physical health owing to the burden resulting from the relative’s functional disabilities, cognitive impairment [27, 47, 48], medication management [49] duration of care [43, 50] and total daily hours spent on assisting patients with basic activities of daily
living and medical tasks [12, 50–52]. Caring for their relative can leave family members overwhelmed and physically exhausted [53, 54], which may result in compassion fatigue. It is not the total number of years of caregiving that contributed to differences in compassion fatigue, but the number of hours per week [55], suggesting that

Fig. 2 Instruments used in the reviewed studies to measure the impact of the disease on family members/partners. ZCBS: Zarit Caregiver Burden Scale; WHOQOL: The World Health Organization Quality of Life; SF36: The Short Form (36) Health Survey; SF12: 12-item Short Form Health Survey; IOF: Impact on Family Scale; EQ-5D: Euroqol-5 Dimension; PedsQL 2.0 FIM: PedsQL TM 2.0 Family Impact Module; DFI: Dermatitis Family Impact questionnaire; CBS: Caregiver Burden Scale; CarerQol-7D: Care-related Quality of Life instrument-7 Dimension; BDI: Beck Depression Inventory; FDLQI: Family Dermatology Life Quality Index; CQOLC: Caregiver Quality of Life Index-Cancer; HADS: Hospital Anxiety and Depression Scale; CQOLCF: Caregiver Quality of Life Cystic Fibrosis; IES: The Impact of Event Scale; CRA: The Caregivers Reaction Assessment Scale; CES-D: Centre for Epidemiologic Studies Depression Scale; COH-QOL: City of Hope Quality of life Questionnaire; NHP: The Nottingham Health profile questionnaire; FIQ: Family Impact Questionnaire; PSI: The Parenting Stress Index Questionnaire; WPAI-SHP: The Work Productivity and Activity Impairment-Specific Health Problem V2.0; QoLFQ: Qol Family Questionnaire; HAMD: Hamilton Depression Scale; CGSQ: the Caregiver Strain Questionnaire; ProQol: Professional Quality of Life; GDS: Geriatric Depression Scale; GDS-15: Geriatric Depression Scale-15; CQOLC-LT: Caregiver Quality of life index-Liver Transplantation; IADL subscale: Instrumental Activities of Daily Living; TAAQOL: TNO-AZL Questionnaire for Adult Health-Related Quality of life; CHQ-PF: Child Health Questionnaire-Parent Form; SPQ: Sibling Perception Questionnaire; CHQ-CF87: Child Health Questionnaire-Child Form 87; CESD-R: Centre for Epidemiologic Studies Depression Scale (revised); CMCRD: Caring for my Child with a Juvenile Rheumatic Disease; LSRS: Lifespan Sibling Relationship scale; DOBI: Dutch Objective Burden Inventory; CHQ-PF50: Child Health Questionnaire-Parent Form 50; PECI: Parent Experience of Child Illness; WFF: Work-Family Facilitation scale; WFC scale: Work-Family Conflict scale; PedsQLTM: Pediatric Quality of Life Inventory TM; HEMOCAB: Hemophilia Associated Caregiver Burden Scale; BAS: Burden assessment Scale; BAI: Becks Anxiety Inventory; MCSI: Modified version of Caregiver Strain Index
intensity of caring rather than duration is the critical factor. Furthermore, family members of people with less severe chronic diseases reported only a moderate burden on QoL [56, 57], indicating that caregiving burden is related to the severity of the patient’s disease and the family member’s perception of burden [35, 58].

Sleep
The physical health of family members caring for their relative was impacted by poor sleep quality [59–64]. Meltzer et al. [61] found that parents of ventilator-assisted children experienced shorter sleep duration and greater variability in sleep quality impacting their physical health compared to parents of healthy children. In the mothers of children with Duchenne muscular dystrophy, impaired sleep quality was related to the disease duration [62], while the sleep disturbance in the parents of children with atopic disease was related to the children’s sleep disruption [63]. The partners of cancer patients experienced poor sleep quality: there was a significant correlation between patients’ and their partners’ sleep quality and sleep onset latency [60]. Although partners used medication to minimise the negative impact of sleep problems, Chen et al. [60] argue that this could have affected their ability to respond to the needs of the patient, indicating that many family members may be hesitant to use drugs to aid sleep.

Impact on social, leisure and daily activities
Family members caring for a relative with a chronic condition experience a considerable impact on their social, leisure and daily activities [38, 51, 58, 65, 66], with women reporting greater disruption than men [67]. Most family members caring for their relative reported difficulties in combining caring tasks with daily activities [29, 68, 69].

Parents of children with chronic disease reported less opportunity for leisure and social activities [38, 53, 68, 70]. The high caregiving demands of children with developmental disabilities, especially if outwardly visible, contributed to social isolation [33]. The parents of children with obsessive compulsive disorder experienced interruptions in social life such as postponing social activities [71]. Parents of children receiving palliative care felt little desire to go out, indicating that the severity of their child’s disease led to a loss of interest in leisure activities [72].

There seems to be a cultural aspect to the impact of caregiving on social life. Japanese caregivers reported
high social scores on the Zarit burden scale [73], even when their perception of general health was lower than that of the care recipient. This indicates that unlike Western caregivers, Japanese caregivers do not report their feelings about their social life being impacted by caregiving [73]. Arab mothers of children with disabilities experienced reduced social interactions and lower QoL due to the cultural beliefs and the stigma attached to having a child with a disability [48].

**Impact on family relationships**
A relative’s chronic condition has an impact on the relationships among family members and between the patient and the family members [29, 74, 75]. Caring for a family member not only impacts the carer but also the whole family [16, 76] and better family relationships improved QoL for both patient and family members [35, 69, 77].

Mothers caring for children with attention deficit hyperactivity disorder and oppositional developmental disorder (ODD) experienced negative feelings towards their affected child. Some mothers attributed their child’s ODD to increased conflicts between them and their partners [74]. However, having more children was seen as being protective against partner conflict and maternal hostility, as siblings could assist the mother by caring for the sick child, thereby reducing parental stress and negative feelings towards the child [74]. Conversely, siblings may internalise their emotional reactions to the situation, leading to behavioural problems [40]. Better alignment and coordination between parents and involving the siblings, however, could lead to family cohesion, tackling the problem together.

Partners of patients experienced poor sexual life and relationship quality because of the patient’s symptoms [68, 78], with a significant decrease in the partners’ ability to spend quality time with the patient [70], leading to marital conflicts [68]. For many, the caregiving role restricted them from having more children [72]. Knap et al. [72] reported that 48% of parents of children with life-limiting illnesses choose not to have more children because of their child’s illness and associated caring responsibilities.

**Financial impact**
Caring for a relative with a chronic disease can necessitate increased expenditure [15, 31, 67, 68, 79–83]. In an Australian study, the annual personal cost for mild, moderate, and severe atopic dermatitis was calculated at Aus$330, 818, and 1255, respectively, with most being spent on medication, dressings and non-irritant clothing [64]. In a Swedish study, 20% of parents reported experiencing financial difficulties even after the cost of the chronic disease treatment was covered by the welfare system [84]. The family members reduced their working hours or left their jobs to take up their caring responsibilities. This and the expense of hospital visits contributed to their financial difficulties [64, 84, 85].

**Impact on work**
Work was seen to have a positive impact on the QoL of mothers, as it provided temporary relief from their caring role, time to socialise and offset the financial burden [47, 71]. However, many family members caring for their relative suffered work impairment [75, 86] and had to give up their jobs, change jobs, alter career choices or reduce their work hours to look after an ill family member and to manage hospital visits [64, 70, 87, 88].

**Positive aspect of caregiving**
Despite the physical, social and psychological impact that a relative having a disease has on family members, many family members reported a positive experience of caregiving, with older family members reporting more satisfaction than younger ones [55]. Meriggi et al. [67] reported 93.5% family members caring for their relative were happy with their role. Son et al. [77] attribute positivity in family members caring for cancer patients to their spiritual upliftment. Awadalla et al. [89] attribute this positive impact to family cohesion, and an attitude of hopefulness. Adult siblings caring for their parents reported that they see caregiving as a way of giving something back to parents [90]. Although the health status of family members with caring experience was lower than that of non-carers in an Australian study, the difference in scores did not reach the minimal important difference (MID) magnitude for either the mental or physical domains of SF-12, suggesting that caregivers might be satisfied in their caring roles [91].

**Existing family QoL instruments**
The appraisal of the family QoL measures identified 48 instruments measuring the impact of a patient’s disease on family members. Forty-two of the instruments are disease or speciality specific and are limited to that particular group of patients. The properties of these measures are summarised in Tables 1 and 2.

The review also identified Six population-specific/generic measures: their properties are summarised in Tables 3 and 4. Five of these measures (Impact on Family Scale, the Beach Centre Family Quality of Life, the PedsQL™ Family Impact Module, Family Quality of Life Survey and Care-related QoL), are aimed at specific populations of carers (parents of children, family members of people with disability, informal caregivers not necessarily family members of people with long term conditions).
| Name of measure/key references | Country | Disease/ speciality | Population | Language/ translation | Completion time | Origin | Domains | Number of items | Scale | Mode of administration |
|-------------------------------|---------|---------------------|------------|-----------------------|----------------|--------|---------|-----------------|-------|------------------------|
| 1. Family Dermatology Life Quality Index (FDLQI) | UK | Speciality-specific (Dermatology) | Family members of patients with skin disease | English/Italian, Persian and Ukrainian | 2–3 min | Semi-structured interviews with family members or partners of patients with a variety of skin diseases | Emotional and physical wellbeing, relationships, social life, leisure activities, burden of care, impact on job study, housework and expenditure | 10 | 4-point Likert | Self-report |
| 2. Dermatitis Family Index (DFI) | UK | Disease-specific (Dermatitis) | Parents and other family members of children with Atopic Dermatitis | English/Arabic, Chinese, Czech, Dutch, French, Greek, Italian, Japanese, Norwegian, Polish, Portuguese, Spanish, Swedish, Ukrainian | 2–3 min | Qualitative interviews with family members/ focus group | Housework, food preparation and feeding, sleep, family leisure activities, time spent on shopping for the family, expenditure, tiredness, emotional distress, relationships between the main carer and partner or between the main carer and other children and helping with treatment | 10 | 4-point Likert | Self-report |
Table 1 (continued)

| Name of measure/key references | Country | Disease/speciality | Population | Language/translation | Completion time | Origin | Domains | Number of items | Scale | Mode of administration |
|-------------------------------|---------|--------------------|------------|----------------------|----------------|--------|---------|------------------|-------|----------------------|
| 3. Parents’ Index QoL Atopic Dermatitis (PiQoL) | UK, Netherlands, Germany, Italy, Spain, France, USA, Switzerland | Disease-specific (Atopic Dermatitis) | Caregiver of children with Atopic Dermatitis, aged 8 years or younger | English/Dutch, Italian, French, German, Spanish | 4–5 min | Qualitative interviews with parents of children with Atopic dermatitis in the UK, Netherlands and Italy | Needs that can be influenced by a child having atopic dermatitis (e.g., need for child to have a safe and successful future, need for rest and relaxation, need for self-respect, need for independence) | 28 | Dichotomous | Self-report |
| 4. QoL in primary caregivers of children with atopic dermatitis (QPCAD) | Japan | Disease-specific (Atopic Dermatitis) | Primary caregivers of children with atopic dermatitis | English | 1–2 min | Semi-structured interviews | Four domains: Exhaustion, worry about atopic dermatitis, family cooperation, and achievement | 19 | 5-point Likert | Self-report, mail |
| 5. Childhood Atopic Dermatitis Impact Scale (CADIS) | USA | Disease-specific (Atopic Dermatitis) | Children with Atopic dermatitis younger than six years and their families | English | 6 min | Focus groups with parents and expert & Lit review | Five domains, three of whom refer to the impact on the family: family and social function, sleep, and emotions | 45 | 5-point Likert | Self-report |
| Name of measure/key references | Country | Disease/speciality | Population | Language/translation | Completion time | Origin | Domains | Number of items | Scale | Mode of administration |
|--------------------------------|---------|--------------------|------------|----------------------|----------------|--------|---------|-----------------|-------|-----------------------|
| 6. Psoriasis Family Index (PFI) Eghlileb et al. [102]; Basra et al. [103] | UK      | Disease-specific (Psoriasis) | Family members of psoriasis patients | English | 2–3 min | Interviews with relatives of people with psoriasis | Frustration, worry about the reaction of other people, worry about their future, relationships, housework due to psoriasis and to treatment, time spent on treatment, social life, sporting activities, leisure activities, type of clothes, routine shopping and sleep | 14  | 4-point Likert Self-report |
| 7. Atopic dermatitis Burden Scale (ABS) Méni et al. [104] | France  | Disease-specific (Dermatology) | Parents of children with Atopic dermatitis (AD) | French, English, US, German, Italian, Spanish, Romanian and Georgian | NF | Literature review; educational workshop/discussion groups with parents of children with AD; feedback from expert HCPs/Parent association AD | Four domains: Family life, budget & work, daily life and treatment | 14  | 4-point Likert Self-report |
| Name of measure/key references | Country   | Disease/speciality | Population | Language/translation | Completion time | Origin | Domains                                                                 | Number of items | Scale   | Mode of administration |
|-------------------------------|-----------|--------------------|------------|----------------------|----------------|--------|------------------------------------------------------------------------|----------------|---------|------------------------|
| 8. Haemangioma Family Burden (HFB) questionnaire Boccara et al. [105] | France    | Disease-specific (Dermatology) | Parents of children with Infantile haemangioma (IH) | French/US and UK English, Spanish, Italian and German | NF            | Literature review, interviews with healthcare professionals (paediatricians, dermatologists, nurses) and with the parents of children that have or have had IH of varying severity | 20             | 3-point Likert         | Self-report |
| 9. FamilyPso Mrowietz et al. [106] | Germany   | Disease-specific  | Partners or family of psoriasis patient | English | NF            | Literature reviews and interviews with relatives of people with psoriasis | 15             | 5-point Likert         | Self-report |
| Name of measure/key references | Country  | Disease/speciality | Population | Language/translation | Completion time | Origin | Domains | Number of items | Scale | Mode of administration |
|--------------------------------|----------|--------------------|------------|----------------------|----------------|--------|---------|----------------|-------|----------------------|
| 10. Epidermolysis Bullosa Burden of Disease (EBBoD) | France   | Disease-specific (Epidermolysis Bullosa) | Families of children with epidermolysis bullosa (EB) | French | NF | Verbatim report based literature review and data collection from parents of patients during a one-to-one session with the same social worker | Four domains- Family life, child’s life, disease and treatment, and economic and social impact | 20 | 7-point Likert | Self-report |
| 11. Family Burden Ichthyosis (FBI) | France   | Disease-specific (Ichthyosis) | Families of children with Ichthyosis | French | NF | Literature reviews and interviews with patients, parents and experts | Five domains- Economic, daily life, familial and personal relationship, work and psychological impact | 25 | 4-point Likert | Self-report |
| 12. Family burden of Incontinentia pigmenti (IP) F’BoIP questionnaire | France   | Disease-specific (Dermatology) | Parents/family members of children with IP condition | French/US English | NF | Interviews with dermatologists, patient-reported outcome (PRO) experts and IP parents | Four domains -Social life and family life, Professional life and renunciation, Daily life and Economic impact | 20 | 6-point Likert | Self-report |
| 13. Parents’diabetes QoL Questionnaire (PDQoL) Vandagriff et al. [110], Faulkner et al. [111] | USA      | Disease-specific (Diabetes Type 1) | Parents of children with type 1 diabetes | English | NF | Three domains- Life satisfaction, impact of disease, and worries related to the disease | | 42 | 5-point Likert | Self-report |
| Name of measure/key references | Country | Disease/speciality | Population | Language/translation | Completion time | Origin | Domains | Number of items | Scale | Mode of administration |
|--------------------------------|---------|--------------------|------------|----------------------|----------------|--------|---------|----------------|-------|---------------------|
| 14. Well-being and Satisfaction of CAREgivers of children with Diabetes Questionnaire (WE-CARE) Cappelleri et al. [112] | USA | Disease-specific (Diabetes Type 1) | Primary caregivers and parents of children with Diabetes type 1 | English/Portuguese/Spanish/Swedish | 10–15 min | Interviews with children and caregivers/paediatricians | Four domains: Psychosocial well-being, ease of Insulin use, treatment satisfaction, and acceptance of Insulin administrations | 37 | 5-point Likert | Self-report |
| 15. Diabetes family impact scale (DFI-S) Katz et al. [113] | USA | Disease-specific (Diabetes Type 1) | Parents of children and adolescents with type 1 diabetes | English | NF | Interview with parents of children with diabetes and multidisciplinary expert panel | Four domains: School, work, finances and family well-being | 14 | 4-point Likert | Self-report |
| 16. Parent Ear Nose and Throat QoL questionnaire (PAR-ENT-QoL) Berdeaux et al. [114] | France, Italy, Germany, Czech Republic, Portugal | Speciality-specific (Ear-nose-throat infection/pharyngitis) | Parents of children with ENT infections | France, Italy, Germany, Czech, Portugal | 5 min | Interviews with families | Three domains: an emotional score, a daily disturbance score, and a global score | 14 | 5-point Likert | mail |
| 17. Food Allergy Quality of Life Parent Burden (FAQLO-PB) Cohen et al. [115] | USA | Disease-specific (Food Allergy) | Parents of children with Food allergy | English/Chinese | 5–7 min | Interviews/ focus groups with caregivers | Three domains: issues concerning going on vacation, social activities and worries and anxieties over the previous week | 17 | 7-point Likert | mail |
| Name of measure/key references | Country | Disease/speciality | Population | Language/translation | Completion time | Origin | Domains | Number of items | Scale | Mode of administration |
|-------------------------------|---------|--------------------|------------|----------------------|----------------|--------|---------|-----------------|-------|-----------------------|
| 18. Caregiver Quality of Life Cystic Fibrosis (CQOLCF) Boling et al. [116] | USA | Disease-specific (Cystic Fibrosis) | Caregivers Patients with Cystic Fibrosis | English | 7–8 min | Expert review/care staff team | Four domains: The physical well-being, emotional well-being, social/family well-being, and functional well-being | 35 | 5-point Likert | Telephone |
| 19. OverActive Bladder Family Impact Measure OAB-FIM Coyne et al. [117] | USA | Disease-specific (Overactive Gall Bladder) | Family members of a patient with Overactive bladder | English Spanish Turkish | NF | Focus group with Family members of patients with Overactive bladder | Six domains: (Irritation, activities, travel, concern) for all family members and sleep, sex for spouses and significant others | 19 | 5-point Likert | Self-report |
| 20. ITP-Idiopathic thrombocytopenic purpura—Parental Burden QoL questionnaire (ITP—PB) Barnard et al. [118] | Canada, USA | Speciality specific (Hematologic disorder) | Parents of children with a hematologic disorder | English | 5–7 min | Interview with parents/health professionals | Six domains: concerns related to diagnosis/investigation, treatment/disease monitoring, monitoring of child’s activities, interference with daily life, disease outcome, and emotional impacts | 26 | 5-point Likert | Self-report |
Table 1 (continued)

| Name of measure/key references | Country | Disease/speciality | Population | Language/translation | Completion time | Origin | Domains | Number of items | Scale | Mode of administration |
|--------------------------------|---------|--------------------|------------|----------------------|----------------|--------|----------|----------------|-------|-----------------------|
| 21. Huntington’s disease quality-of-life battery for carers (HDQoL-C) Aubeeluck & Buchanan [119] | UK | Disease-specific (Huntington’s disease) | Family caregivers of persons with Huntington’s Disease | English | 21 min | Qualitative interview/Photovoice | Four domains-Demographic and objective information; practical aspects of caregiving; satisfaction with life; feelings about living with Huntington’s disease | 34 | 11-point Likert | Self-report |
| 22. Huntington’s disease quality-of-life battery for carers short form (HDQoL-C-SF) Aubeeluck et al. [120] | France, Italy | Disease-specific (Huntington’s disease) | Family caregivers of persons with Huntington’s Disease | English/French, Italian, German, Polish, Portuguese, Spanish and Swedish, | NF | 312 carers from France and Italy completed HDQoL-C to develop a shortened version of the HDQoL-C | Two domains-Satisfaction with life; feelings about living with Huntington’s disease | 20 | 11-point Likert | Self-report |
| 23. Alzheimer’s Carers Quality of Life Instrument (ACQLI) Doward [121] | UK, France, Germany, Italy, Spain | Disease-specific (Alzheimer’s) | Carers of patients with Alzheimer’s disease | English | NF | | The single domain of carer QoL | 30 | Dichotomous (true/not true) | Self-report |
| 24. Care related Quality of care—Multiple Sclerosis (CAREQOL-MS) Benito-Leon et al. [122] | Spain | Disease-specific (Multiple Sclerosis) | Caregivers of Multiple Sclerosis | English/Spanish | NF | Focus groups were organized with MS patients and caregivers/MS expert | Five domains-Physical burden and global health; social impact; emotional impact; need of support; emotional reactions to patient’s psychic status | 24 | 5-point Likert | Self-report |
| Name of measure/key references | Country | Disease/speciality | Population | Language/translation | Completion time | Origin | Domains | Number of items | Scale | Mode of administration |
|-------------------------------|---------|--------------------|------------|----------------------|----------------|--------|---------|-----------------|-------|-----------------------|
| 25. Parkinson Disease Questionnaire for Carers (PDQ-Carer) Jenkinson et al. [123] | UK | Disease-specific (Parkinson Disease) | PD carers | English | NF | Carer Surveys registered with local branches of Parkinson's UK | Four domains: Social and personal activities, anxiety and depression, self-care, stress | 29 | 5-point Likert | Self-report |
| 26. Parkinson Disease Questionnaire for Carers Summary Index (PDQ-Carer-SI) Morley et al. [124] | UK | Disease-specific (Parkinson Disease) | PD carers | English | NF | Carer Surveys registered with local branches of Parkinson's UK | Single summary index score computed using the four subscales of the PDQ-Carer | 29 | 5-point Likert | Self-report |
| 27. Parkinsonism Carers QoL (PQoL Carers) Pillas et al. [125] | UK | Disease-specific (Atypical Parkinsonism) | Relatives/partner of patients with atypical Parkinsonism (AP) | English | NF | Qualitative interviews with relatives/partner of a person with AP and Consultation with AP experts | Single domain of carer QoL | 26 | 5-point Likert | Self-report |
| 28. Family Outcome Measure –40 (FOM-40) Migliorini et al. [126] | Australia, New Zealand, Canada, UK | Disease-specific (Traumatic brain injury) | Families with relative having a traumatic brain injury | English | NF | Social workers from 12 rehabilitation centres across Australia, New Zealand, Canada, and the UK | Seven domains: Family member coping, family cohesion, support demands (burden), relative adjustment, adequacy of service, family member resilience, sustainability of family support | 40 | 4-point Likert | Self-report |
| Name of measure/key references | Country | Disease/speciality | Population | Language/translation | Completion time | Origin | Domains | Number of items | Scale | Mode of administration |
|--------------------------------|---------|--------------------|------------|----------------------|----------------|--------|--------|-----------------|-------|----------------------|
| 29. Caregiver Quality of life (CGQOL): Vickrey et al. [127] | USA | Disease-specific (Dementia) | Family caregivers of people with Dementia | English | 17 min | Interviews with carers of Dementia Patients | Ten Domains; Assistance with instrumental activities of daily living; assistance with activities of daily living; role limitations due to caregiving; personal time; family interaction; demands of caregiving; worry; spirituality and faith; benefits of caregiving; caregiver feelings | 80 | 3-point and 5-point Likert | Telephone interview |
| 30. Caregiver Dementia Quality of Life (C-DEMQOL): Brown et al. [128] | UK | Disease-specific (Dementia) | Family members of people with Dementia | English | 15 min | Literature reviews/ qualitative interviews with family carers and support staff, Focus groups with carers and staff | Five domains- Responsibilities and personal needs; well-being; carer role and relationships with the person with dementia; feelings about future and carer support | 30 | 5-point Likert | Researcher administered/Self-report |
| Name of measure/key references | Country  | Disease/speciality | Population | Language/translation | Completion time | Origin | Domains | Number of items | Scale | Mode of administration |
|-------------------------------|---------|-------------------|------------|---------------------|----------------|--------|---------|-----------------|-------|----------------------|
| 31. Family Impact Scale-Oro-facial (FIS—OFD) | Canada | Disease-specific (Oro-facial Disorder) | Parents of children with Oro-facial conditions | English | 5 min | Review of existing child health status and family impact questionnaires, interviews with 41 parents/caregivers | Four domains—Parental and family activity, parental emotions family conflict and financial burden | 14 | 5-point Likert | Self-report |
| 32. Quality of Life in life-Threatening Illness—Family Carer Version (QoLLTI–F) | Canada | Speciality specific (Oncology) | Caregivers of cancer patients receiving palliative care | English/French | < 10 min | Previous research and expert review | Seven domains—Carer’s own state, relationships, carer outlook, quality of care, patient condition, finances, environment | 16 | 11-point Likert | Self-report |
| 33. CareGiver Oncology Quality of Life questionnaire (CarGOQol) | USA | Speciality specific (Oncology) | Caregivers of cancer patients | English/French | 6 min | Qualitative interviews with informal caregivers of cancer patients | Ten domains—Psychological wellbeing, burden, relationships with healthcare, administration and finances, coping, physical well-being, Self-esteem, leisure time, social support and private life | 29 | 5-point Likert | Self-report |
| Name of measure/key references | Country | Disease/speciality | Population | Language/translation | Completion time | Origin | Domains | Number of items | Scale | Mode of administration |
|--------------------------------|---------|--------------------|------------|----------------------|-----------------|--------|---------|--------------|-------|--------------------|
| 34. Caregiver Quality of Life Index–Cancer Weitzner et al. [132] | USA | Oncology | Primary caregiver of cancer patients | English, Turkish, Korean, Chinese | 10 min | A semi-structured interview with family caregivers, physicians, nurses and social/Expert Review | Four domains- Burden, disruptiveness, positive adaptation, and financial concern | 35 | 5-point Likert | Self-report |
| 35. City of Hope QoL Scale–Family Version Ferrell et al. [133] City of Hope [134] | USA | Speciality-specific (Oncology) | Family caregivers of cancer patients | English and Spanish | NF | In-depth qualitative interviews with cancer survivors over five years Pilot | Four domains- Physical, psychological, social, spiritual | 37 | 11-point Likert | Self-report, mail |
| 36. Caregiver Impact Questionnaire (CIQ Survey Otitis media) Boruk et al. [135] | USA | Disease-specific (Acute Otitis Media) | Parents of children with acute otitis media | English | NF | Previous research/Expert Panel/parents/non-medical volunteer | Four domains- Caregiver physical functional health status (FHS), caregiver emotional FHS, & caregiver QoL rating and sibling impact score | 10 | Mix of 7 and 5-point Likert and visual-analog scale | Self-report |
Table 1 (continued)

| Name of measure/key references | Country | Disease/speciality | Population | Language/translation | Completion time | Origin | Domains | Number of items | Scale | Mode of administration |
|--------------------------------|---------|--------------------|------------|----------------------|----------------|--------|---------|------------------|-------|----------------------|
| 37. Acute Otitis Media QoL questionnaire (AOM) | Canada | Disease-specific (Otitis Media) | Parents and children with Otitis media | English/French | 10 min | Developed base on two already validated questionnaires | Four domains (sleep deprivation, change of daily and social activities, emotional distress, cancelling family plans and trips) and two domains assessing adverse consequences for the siblings and Caregiver overall QOL | 13 | 4-point Likert and 5-point Likert | Telephone |
| 38. Pediatric Asthma Caregivers’ Quality of Life Questionnaire (PACQLQ) | Canada | Disease-specific (Asthma) | Caregivers of children with asthma | English/Spanish, Swedish, French, Portuguese, Bulgarian, Danish, Finnish, German, Chinese, Hungarian, Hebrew, Dutch, Norwegian, Persian, Polish, Russian, Serbian, Afrikaans, Arabic | 3–5 min | Unstructured interviews with parents of children with asthma, a literature review and discussion with health professionals | Two domains-Activity limitations and emotional function | 13 | 7-point Likert | Self, internet, hardcopy |
| 39. Influenza-like illness Quality of Life (Care-ILI-QoL) | Australia | Specialty-specific (Respiratory and infection disease) | Parents of Children With Influenza-Like Illness | English | NF | Quantitative survey, qualitative interviews with parents and meetings with paediatricians | Four domains-Daily activities, perceived support, social life, and emotions | 16 | 7-point Likert | Self-report |
| Name of measure/key references | Country | Disease/speciality | Population | Language/translation | Completion time | Origin | Domains | Number of items | Scale | Mode of administration |
|-------------------------------|---------|--------------------|------------|----------------------|----------------|--------|---------|----------------|-------|----------------------|
| 40. CAREGIVERS questionnaire Juvenile Idiopathic Arthritis (JIA) Torres-Made et al. [140] | Mexico | Disease-specific (Juvenile idiopathic arthritis) | Caregivers of children with JIA | Spanish/English | NF | Non-systematic Lit review/semi-structured interview with primary caregivers/multidisciplinary group input | Eight domains: Disease impact, social impact, economic and working impact, family impact, impact on caregiver-patient relationship, impact on couple relationship, impact on spirituality/religion/personal beliefs, impact on social networks | 28 | Mixed Likert/dichotomous | Self-report |
| 41. CD parent/caregiver QoL questionnaire (CDPC-QOL) Abreu Paiva [141] | Brazil | Disease-specific (Celiac Disease) | Parents and caregivers of children and adolescent with Celiac disease | Brazilian-Portuguese | 6 min | Developed based on Literature review, researchers experience and reviewing other QoL questionnaires | Three domains: Emotions, worries, and social | 30 | 5-point Likert | Self-report |
| 42. Family Caregiver Quality of Life (FAMQOL) Scale [142] | USA | Disease-specific (Heart Disease-Heart Failure) | Caregivers of Heart Failure patients | English/Turkish | NF | Developed through interview with caregivers/experts | Four dimensions: Physical, psychological, social, and spiritual | 16 | 5-point Likert | Self-report |
Table 2  Psychometric properties of family quality of life measures – disease/speciality specific

| Name of the measure/key references | Country | Disease/speciality | Internal consistency (Cronbach’s alpha) | Test–retest | Content | Construct/ convergent | Construct/ divergent/ discriminant | Criterion | MID | Responsiveness/ sensitivity to change |
|------------------------------------|---------|--------------------|-----------------------------------------|------------|---------|----------------------|-------------------------------------|-----------|-----|-------------------------------------|
| 1. Family Dermatology: Life Quality Index (FDLQI) | UK      | Specialty Specific (Dermatology) | Yes, ($\alpha = 0.88$) | Yes, $r = 0.94$ | Yes | Yes | NF | NF | NF | Yes |
| 2. Dermatitis Family Index (DFI) | UK      | Disease Specific (Dermatitis) | Yes, $\alpha = 0.85$ to 0.90, | Yes, ($r = -0.95$) | Yes | Yes | NF | NF | NF | Yes |
| 3. Parental Index QoL Atopic Dermatitis (PIQoL) | UK, Netherlands, Germany, Italy, Spain, France, USA, Switzerland | Disease-Specific (Atopic Dermatitis) | Yes, $\alpha = 0.88$ and 0.93 | Yes, $> 0.85$ | Yes | Yes | NF | NF | Yes | Yes |
| 4. QoL in primary caregivers of children with atopic dermatitis (QPCAD) Kondo-Endo et al. [98] Katsunuma et al. [99] | Japan | Disease Specific (Atopic dermatitis) | Yes($\alpha = 0.66-0.87$) | Yes, ($r = 0.80-0.87$) | Yes | Yes | NF | NF | NF | Yes |
| 5. Childhood Atopic Dermatitis Impact Scale (CADIS) Chamlin et al. [100] Chamlin et al. [101] | USA | Disease-Specific (Atopic dermatitis) | Yes, ($\alpha = 0.76-0.93$) | Yes, $r = 0.96$ | Yes | Yes | Yes, discriminant | NF | NF | Yes |
| 6. Psoriasis Family Index (PFI) Eghlileb et al. [102, 104], Basra et al. [103] | UK | Disease-Specific (Psoriasis) | Yes, $\alpha = 0.86$ | Yes, $r = 0.93$ | Yes | NF | NF | NF | NF | NF |
| 7. Atopic dermatitis Burden Scale (ABS) | France | Specialty-specific (Dermatology) | Yes, $\alpha = 0.78$ | NF | Yes | Yes | Yes, concurrent and discriminant | NF | NF | NF |
| 8. Haemangioma Family Burden (HFB) questionnaire [105] | France | Specialty-specific (Dermatology) | Yes, $\alpha = 0.93$ | NF | Yes | Yes | Yes, concurrent and discriminant | NF | NF | NF |
| 9. FamilyPso Mrowietz et al. [106] | Germany | Dermatology | Yes, $\alpha = 0.88$ | NF | Yes | Yes | Yes, discriminant | NF | NF | NF |
| No. | Name of the measure/key references | Country | Disease/speciality | Internal consistency (Cronbach’s alpha) | Test–retest | Content | Construct/convergent | Construct/divergent/discriminant | Criterion | MID | Responsiveness/sensitivity to change |
|-----|-----------------------------------|---------|-------------------|------------------------------------------|-------------|---------|----------------------|---------------------------------|-----------|-----|-----------------------------------|
| 10  | Epidermolysis Bullosa Burden of Disease (EBBoD) | France | Disease-Specific (Epidermolysis Bullosa) | Yes, α = 0.90 | Yes, r = 0.97 | Yes | Yes | Yes, discriminant | NF | NF | NF |
| 11  | Family Burden of Ichthyosis (FBI) | France | Disease-Specific (Ichthyosis) | Yes, α = 0.89 | NF | Yes | Yes | Yes, discriminant | NF | NF | NF |
| 12  | Family burden of Incontinentia pigmenti F’BoIP questionnaire [109] | France | Speciality-specific (Dermatology) | Yes, α = 0.93 | Yes, ICC = 0.85 for each domain | Yes | Yes | Yes | NF | NF | NF |
| 13  | Parents/Diabetes QoL Questionnaire (PDQol) Vandagriff et al. [110]; Faulkner et al. [111] | USA | Disease-Specific (Diabetes Type 1) | Yes, α = 0.64–0.09 | NF | NF | NF | Yes, discriminant | NF | NF | NF |
| 14  | (WE-CARE) Cappellieri et al. [112] | USA | Disease-Specific (Diabetes Type 1) | Yes, α = 0.84–0.95 | Yes, r = 0.80–0.88 | Yes | Yes | Yes | NF | NF | NF |
| 15  | Diabetes family impact scale (DFI-S) Katz et al. [113] | USA | Disease-specific (Diabetes Type 1) | Yes, α = 0.8 | NF | Yes | Yes | NF | NF | NF |
| 16  | Parent Ear Nose and Throat QoL questionnaire (PARENT-QoL) Bendeaux et al. [114] | France, Italy, Germany, Czech Republic, Portugal | Speciality specific (Ear-nose-throat infection/pharyngitis) | Yes, α = 0.80–0.093 | NF | Yes | Yes | Yes | NF | NF | NF |
| 17  | FAQLQ-PB Cohen et al. [115] | USA | Disease-specific (Food Allergy) | Yes, α = 0.95 | Yes, r = 0.93, | Yes | Yes | Yes | NF | NF | NF |
| 18  | Caregiver Quality of Life Cystic fibrosis (CQOLCF) Boling et al. [116] | USA | Disease-specific (Cystic fibrosis) | Yes, α = 0.91 | Yes, r = 0.862, | Yes | Yes | Yes, discriminant | Yes | NF | NF |
| 19  | OverActive Bladder Family Impact Measure OAB-FIM Coyne et al. [117] | USA | Disease-specific (Overactive Gall Bladder) | Yes, α = 0.89 or greater for all sub-scales except for one 0.71 | Yes, r = 0.70–0.87 ICC = 0.73 to 0.87 | NF | Yes | Yes | NF | NF | NF |
| Name of the measure/key references | Country                  | Disease/speciality                          | Internal consistency (Cronbach’s alpha) | Test–retest               | Content          | Construct/ convergent | Construct/ divergent/discriminant | Criterion | MID | Responsiveness/ sensitivity to change |
|----------------------------------|--------------------------|---------------------------------------------|----------------------------------------|---------------------------|-----------------|----------------------|----------------------------------|-----------|-----|-------------------------------------|
| 20. ITP-Parental burden QoL questionnaire (ITP—PB) Barnard et al. 2003 [118] | Canada, USA             | Speciality Specific (Hematologic disorder)  | NF                                     | NF                        | Yes             | Yes                  | Yes, only for subscales $\alpha = 0.80, 0.64, 0.69$ | NF         | NF  | NF                                   |
| 21. HDQoL-C Aubeeluck and Buchanan [119] | UK                       | Disease-specific (Huntington’s disease)     | Yes, only for subscales $\alpha = 0.80, 0.64, 0.69$ | Yes, $r = 0.78, 0.86, 0.90$ for Subscales | Yes             | Yes                  | NF                               | NF         | NF  | NF                                   |
| 22. HDQoL-C SF Aubeeluck et al. [120] | France, Italy           | Disease-specific (Huntington’s disease)      | Yes, only for subscales $\alpha = 0.88, 0.80$ | NF                        | NF              | Yes                  | NF                               | NF         | NF  | NF                                   |
| 23. ACQL Doward, [121]            | UK, France Germany, Italy, Spain | Disease-specific (Alzheimer’s)               | Yes, $\alpha = 0.87$ and 0.95           | Yes                       | Yes             | Yes                  | NF                               | NF         | NF  | NF                                   |
| 24. CAREQOL-MS Benito-Leon et al. [122] | Spain                    | Disease-specific (Multiple Sclerosis)        | Yes, $\alpha = 0.90, 0.85, 0.81, 0.78, 0.75$ for sub-scales | Yes, $r = 0.96$          | Yes             | Yes                  | NF                               | NF         | NF  | NF                                   |
| 25. PDQ-Carer Jenkinson et al. [123] | UK                       | Disease-specific (Parkinson’s Disease)       | Yes, $\alpha = 0.92, 0.87, 0.86, 0.83$ for sub-scales | NF                        | Yes             | Yes                  | NF                               | NF         | NF  | NF                                   |
| 26. PDQ-Carer-SI Morley et al. [124] | UK                       | Disease-specific (Parkinson’s Disease)       | Yes, $\alpha = 0.94$                    | NF                        | NF              | Yes                  | Yes, discriminant                | NF         | NF  | NF                                   |
| 27. PQoLCarers Pillas et al. [125] | UK                       | Disease-specific (Atypical Parkinsonism)     | Yes, $\alpha = 0.96$                    | Yes                       | Yes             | Yes                  | Yes, discriminant                | NF         | NF  | NF                                   |
| 28. FOM-40 Migliorini et al. [126] | UK, Australia, New Zealand, Canada | Disease-specific (Traumatic brain injury)    | NF                                     | NF                        | NF              | NF                   | NF                               | NF         | NF  | NF                                   |
| 29. CGQOL Vickrey et al. [127]    | USA                      | Disease-specific (Dementia)                 | Yes, Subscale $\alpha = 0.88, 0.93, 0.78, 0.83, 0.86, 0.86, 0.82, 0.94, 0.92, 0.89$ | Yes, $r = 0.53–0.89$    | Yes             | Yes                  | Yes, discriminant                | NF         | NF  | Yes                                  |
| 30. C-DEMQOL Brown et al. [128]   | UK                       | Disease-specific (Dementia)                 | Yes, $\alpha = 0.93$                    | NF                        | Yes             | Yes                  | Yes, discriminant                | NF         | NF  | NF                                   |
Table 2 (continued)

| Name of the measure/key references | Country | Disease/speciality | Internal consistency (Cronbach’s alpha) | Test-retest | Content | Construct/convergent | Construct/divergent/discriminant | Criterion | MID | Responsiveness/sensitivity to change |
|-----------------------------------|---------|--------------------|------------------------------------------|-------------|---------|----------------------|----------------------------------|----------|-----|----------------------------------|
| 31. Family Impact Scale—oro-facial disorders (FIS—OFD) | Canada | Disease-specific (Oro-facial disorder) | Yes, α = 0.83 | Yes, r = 0.80 | Yes | Yes | Yes, discriminant | NF | NF | NF |
| 32. Quality of Life in Life-Threatening Illness—Family Carer Version (QoLLTI–F) | Canada | Speciality Specific (Oncology) | Yes, α = 0.86 | Yes, r = 0.77–0.8 | Yes | Yes | NF | NF | NF | NF |
| 33. CareGiver Oncology Quality of Life questionnaire (CarGQOQol) | USA | Speciality Specific (Oncology) | Yes, α = 0.86 | Yes, r = 0.52–0.80 | Yes | Yes | Yes | NF | NF | NF |
| 34. CareGiver Quality of Life Index–Cancer Weitzner et al. | USA | Speciality Specific (Oncology) | Yes, α = 0.91 | Yes, r = 0.95 | Yes | Yes | Yes, divergent | Yes | NF | Yes |
| 35. City of Hope QoL Scale—Family Version Ferrell et al. | USA | Speciality Specific (Oncology) | Yes, α = 0.69 | Yes, r = 0.89 | NF | Factor analysis confirmed the 4 QOL domains as subscales for the instrument | NF | NF | NF | NF |
| 36. CIQ survey Ottis Boruk et al. | English | Disease-specific (Acute Otitis Media) | Yes, α = 0.88 | Yes, r = 0.83, | NF | Yes | NF | NF | NF | NF |
| 37. Acute Otitis Media QoL questionnaire AOM-QoL | Canada | Disease-specific (Otitis Media) | Yes, α = 0.81 | NF | Yes | Yes | Yes, discriminant | NF | NF | NF |
| 38. Pediatric Asthma Caregivers’ Quality of Life Questionnaire PACQLQ | Canada | Disease-specific (Asthma) | NF | Yes, r = 0.84 | Yes | Yes | Yes, discriminant | NF | NF | Yes |
| 39. Influenza-like illness Quality of Life Care-ILI-QoL Chow et al. | Australia | Speciality Specific (Respiratory and infection disease) | Yes, α = 0.72–0.92 | NF | NF | Yes | Yes, discriminant | NF | NF | Yes |
| Name of the measure/key references | Country   | Disease/speciality                                      | Internal consistency (Cronbach’s alpha) | Test–retest | Content | Construct/ convergent | Construct/ divergent/ discriminant | Criterion | MID | Responsiveness/ sensitivity to change |
|----------------------------------|-----------|--------------------------------------------------------|----------------------------------------|-------------|----------|----------------------|-------------------------------------|-----------|-----|-----------------------------------|
| 40. CAREGIVERS questionnaire JIA | Mexico    | Disease-specific (JIA)                                  | Yes, $\alpha = 0.04–0.69$              | Yes         | Yes      | Yes                  | Yes, divergent                      | NF        | NF  | NF                                |
| 41. CD parent/caregiver QoL questionnaire (CDPC-QOL) | Brazil   | Disease-specific (Celiac Disease)                       | Yes, $\alpha = 0.913$                  | Yes, ICC = 0.88 | Yes     | NF                   | NF                                  | NF        | NF  | NF                                |
| 42. Family Caregiver Quality of Life (FAMQOL) Scale | USA      | Disease-specific (Heart Disease-Heart Failure)          | Yes, $\alpha = 0.89$                   | Yes, ICC = 0.91 | Yes     | Yes                  | NF                                  | Yes       | NF  | NF                                |
Table 3  Summary characteristics of family quality of life measures—population specific/generic

| Name of measure/ key references | Country | Population | Language/ translation | Completion time | Origin | Domains | Number of items | Scale (response options) | Mode of administration |
|---------------------------------|---------|------------|-----------------------|-----------------|--------|---------|-----------------|------------------------|------------------------|
| 1. PedsQL™ Family Impact Module | USA     | Parents and the family members of children with Pediatric chronic health conditions | English | NF | Developed and initially field-tested in families with medically fragile children with complex chronic medical conditions | Two domains—Parent functioning with 6 subscales measuring parent’s Self-reported functioning (physical, emotional, social, cognitive, communication worry); and family functioning with 2 subscales (daily activities, family relationships) | 36 | 5-point Likert | Self-report |
| 2. Impact on-Family Scale | USA | Parents of children with chronic illness | English and Spanish | 10 min | Family members interview | Four domains—financial, Social, personal strain and Mastery | 27 (update to 15 items in 2003) | 4-point Likert | Self-report, interviewer administered |
| 3. Beach centre Family Quality of life | USA | Family members of children with disability | English, Spanish, French and Chinese | 15 min | Interview with family members/ focus group | Five domains—Family interaction, Parenting, Emotional Well-being, Physical/Material Well-being | 25 | 5-point Likert | Self-report |
| 4. Care related Quality of Life (CareQoL) | Netherlands | Informal caregivers of Long term Care recipients | English/Dutch, German Norwegian Swedish, Italian, Spanish and Portuguese | NF | Based on EQ-SD and evaluation of caregiver burden scales | Seven general quality of life question domains—five negative and two positive dimensions of providing informal care and VAS scale | 7 and VAS question | 3-point Likert | Self-report |
| Name of measure/ key references | Country | Population | Language/ translation | Completion time | Origin | Domains | Number of items | Scale (response options) | Mode of administration |
|--------------------------------|---------|------------|-----------------------|-----------------|--------|---------|----------------|--------------------------|------------------------|
| 5. Family Quality of life survey-2006, Isaac et al. [149], Perry and Isaac [150], Samuel et al. [151] | Canada | Family members of people with intellectual and developmental disabilities | English, Bosnian, Chinese, Dutch, Farsi, Flemish, French, German, Italian, Japanese, Malaysian, Polish, Romanian, Slovene, Spanish, Telugu | 60 min | Expert opinion and previous research | Nine domains—health, financial well-being, family relationships, support from others, support from services, influence of values, careers, leisure and recreation, and community integration | 54 | 5-point Likert | self-report. Interviewer administered |
| 6. Family Reported Outcome Measure (FROM-16) | UK | Family members of people with any health condition | English/Turkish, Thai, French and German | 2 min | Qualitative interviews with family members of patients with chronic disease, Focus group and Expert panel | Two domains—Emotional, personal and social | 16 | 3-point Likert | Self-report |
The only generic instrument that measures the impact of any condition on family members across all specialities is the FROM-16.

**Discussion**
This review has demonstrated that family members caring for relatives with various chronic diseases are impacted in similar ways in terms of physical, social and psychological wellbeing. The high number of FQoL instruments identified in this review demonstrates a growing interest in FQoL, though most research has focused on a few medical fields including neurology, oncology and dermatology, findings consistent with the previous review [5]. One key strength of this current review is that its findings are based on studies that have used valid tools to measure the impact of a patient’s chronic disease on a family member/partner. The studies included have used many different instruments to

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**Table 4** Psychometric properties of family quality of life measures—population specific/generic

| Name of the measure/ key references | Country | Internal consistency (Cronbach’s alpha) | Test–retest | Content | Construct/ convergent | Construct/ divergent/ discriminant | Criterion | MID | Responsiveness/ sensitivity to change |
|-------------------------------------|---------|----------------------------------------|-------------|---------|------------------------|-----------------------------------|----------|-----|-------------------------------------|
| 1. PedsQLTM family impact module Varni et al. [143]; Scarpelli [153] | USA     | Yes, (α = 0.97) Yes, r = 0.81 to 0.96 | NF          | Yes     | NF                     | NF                                | NF       | NF | NF                                   |
| 2. Impact on-Family Scale (15-item) Stein et al. [144]; Jalil et al. [146] | USA     | Yes, (α = 0.73) Yes, r = 0.9 | Yes         | Yes     | NF                     | NF                                | NF       | NF | NF                                   |
| 3. Beach centre Family Quality of life Posten et al. [6]; Park et al. [147]; Hoffman et al. [154]; Waschl et al. [155]; Rivard et al. [156] | USA     | Yes, α = 0.88–0.94 Yes, for subscale of importance r = 0.41–0.82, for satisfaction subscale, r = 0.60–0.77 | Yes         | Yes     | Yes, divergent and discriminant | NF                                | NF       | NF | Yes (French version)               |
| 4. CareQoL Brouwer et al. [148]; Hoeffman et al. [157]; McCaffrey et al. [158] | Netherlands | Yes, α = 0.65 Yes, Carer 7D r = 0.55–0.94 and Carer VAS, r = 0.86 | NF          | Yes     | Yes, discriminant | NF                                | NF       | NF | NF                                   |
| 5. Family Quality of life survey 2006 Isaac et al. [149]; Perry and Isaac [150], Samuel et al. [151] | Canada  | Yes, α = 0.55–0.78 NF | Yes         | Yes     | NF                     | Yes                                | NF       | NF | NF                                   |
| 6. Family Reported Outcome Measure (FROM-16) Golics et al. [152] | UK       | Yes, α = 0.80–0.89 r = 0.85–0.92 | Yes         | Yes     | NF                     | Yes                                | NF       | NF | NF                                   |
measure the impact of chronic disease on family members, indicating a lack of consensus on the use of instruments: perhaps a clear consensus has not yet emerged because this field is still young. Furthermore, the heterogeneity of the instruments used prevents comparison of the impact of caregiving on family members across disease areas. Such comparison is important in identifying the most vulnerable family members and directing them to appropriate support. This is critical as a physically unhealthy family member would be less able to discharge their caregiving duties, thus having a negative impact on the patients’ health [20]. While many studies in this review have used disease-specific instruments, most used generic health status or population instruments to measure the family impact of a person’s chronic condition, indicating a strong need for a generic QoL measure specific to family members. Furthermore, most instruments used in this review have been designed keeping patients in mind and may not address issues relevant to family members. Using a measure designed to be family-specific should provide a better understanding of the needs of family members, including support services. Disease-specific FQoL instruments are used to assess QoL of family members of people with a specific disease and thus can detect changes in family member's QoL following clinical interventions. Generic FQoL instruments on the other hand, can assess the effects of a wide range of diseases or treatment on the QoL of a partner or family member. Published research has shown that family members caring for relatives with different health conditions are impacted in similar ways [161]. Thus, generic FQoL instruments allow the comparison of QoL of individuals across different disease areas and identification of population-wide trends. While disease-specific instruments can help clinicians to understand the extent to which a partner or family member has been affected by a person's disease and inform appropriate treatment decisions, they cannot be used to compare across conditions or between treatments. Moreover, generic instruments can measure the family impact of disease in areas where there are no disease-specific measures. Some research studies may use both generic and disease-specific instruments to capture the different patient/family member viewpoints or to validate the results of using each type of instrument. The FROM-16 could fill this gap as a generic family outcome measure since it has been developed directly from the experience of family members, for family members. One practical feature of FROM-16 is that it is a user-friendly and relatively simple questionnaire with an average completion time of 2–3 min, making it a practical tool for use in a clinical setting.

There are some limitations of this review. The review is not a systematic review. Although not a systematic review, it followed rigorous methodology and fulfilled 19 relevant PRISMA checklist items (Additional file 2: Table S1) [8]. Besides, the review only included studies in the English language, thus limiting understanding of the impact of patients’ disease on family members in different cultures. Nevertheless, most studies carried out in different cultures are usually published in English language scientific journals; this suggests the amount of missed information may be minimal. Most studies in this review were cross-sectional. Only five studies were longitudinal, revealing that greater carer burden was associated with poor physical and mental health and lower QoL of family members over time, with women being impacted more than men. Future research should focus on longitudinal studies to build understanding of the long-term family impact of disease. This is important as most acute and chronic diseases may influence major life-changing decisions, thus understanding long-term impacts may help clinicians in developing better management plans for patients and their family members [162]. In addition, the majority of family members caring for relatives in the studies reviewed were women, mostly mothers. There is a dearth of research on the impact of caregiving on fathers, although this review highlighted two studies where fathers were impacted more than mothers. The fact that fathers are mostly unavailable at the point of contact results in the impact on fathers being forgotten or difficult to obtain. Thus, future research should focus on the impact of children's diseases on fathers.

An appraisal of existing FQoL instruments identified a recent plethora of FQoL measures indicating the growing recognition of the importance of FQoL. Only a few instruments have published responsiveness and MID information, however evidence of responsiveness is essential for such questionnaires to be useful for clinical monitoring or as an outcome measure to assess the value of interventions. Information concerning MID is important for the clinician to be able to interpret change in scores over time. Most instruments reviewed were developed recently, and perhaps new studies underway might later report their further psychometric properties. Further psychometric testing of existing measures is required. Furthermore, all instruments identified in this review were created in developed countries, highlighting a need for cross-cultural validation in developing countries [163].

Conclusions
In conclusion, this review found that family members caring for their sick relative experience a huge but similar impact on their physical, social and psychological wellbeing across different disease areas. However, to translate
this evidence into practice and support family members impacted by their relative’s disease, there is a need for a generic family QoL measure which offers acceptable practicality and flexibility both to the relatives and to researchers as well as to clinicians. This review has identified FROM-16 as the only generic user-friendly instrument that can be implemented across all disease areas to measure the family impact of a person with a disease. However, to support the use of FROM-16 across all disciplines of medicine, there is a need for further examination of its psychometric properties. Furthermore, with greater digitalisation of healthcare, such information could be captured routinely and combined with that of the patient’s which would, no doubt, enhance the appropriateness of treatment decision-making. There are many reasons why the routine capture of quality of life information concerning patients may be helpful in enhancing the quality of clinical care [164]. Exactly similar potential advantages may be gained by the use of family quality of life measures. The final thought in this context is the utility of such instruments in meeting the aftermath challenges of the current pandemic crisis and impact of Long Covid on families of the survivors.

Abbreviations
QOL: Quality of life; FQOL: Family quality of life; HRQOL: Health-related quality of life; PRISMA: Preferred reporting items for systematic reviews and meta-analyses; ODD: Oppositional developmental disorder; FROM-16: Family reported outcome measure-16; MID: Minimal important difference; NF: Not Found.

Supplementary Information
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Additional file 1. Supplementary tables-methods and results.
Additional file 2. Supplementary table S1-PRISMA Checklist.

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