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## Methodology

# Economic Evaluation of Family-Focused Programs When Parents Have a Mental Health Problem: Methodological Considerations

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## A B S T R A C T

**Objectives:** The nature of adverse effects of parental mental health problems and of the interventions to address them may require specific designs of economic evaluation studies. Nevertheless, methodological guidance is lacking. We aim to understand the broad spectrum of adverse effects from parental mental health problems in children and the economic consequences on an individual and societal level to navigate the design of economic evaluations in this field.

**Methods:** We conducted a systematic literature search of empirical studies on children's adverse effects from parental mental illness. We clustered types of impact, identified individual and public cost consequences, and illustrated the results in an impact inventory.

**Results:** We found a wide variety of short- and long-term (mental) health impacts, impacts on social functioning and socioeconomic implications for the children individually, and adverse effects on the societal level. Consequently, public costs can occur in various public sectors (eg, healthcare, education), and individuals may have to pay costs privately.

**Conclusions:** Existing evaluations in this field mostly follow standard methodological approaches (eg, cost-utility analysis using quality-adjusted life-years) and apply a short-time horizon. Our findings suggest applying a long-term time horizon (at least up to early adulthood), considering cost-consequence analysis and alternatives to health-related quality of life and quality-adjusted life-years as outcome measures, and capturing the full range of possible public and private costs.

**Keywords:** child outcome measures, economic evaluation, parental mental illness.

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## Introduction

Population estimates indicate that over 50% of people with a lifetime diagnosis of mental illness are parents. Up to 60% of people with a severe mental illness live with one or more children.<sup>1,2</sup> International estimates show that 1 in 4 to 1 in 5 children live with a parent who experiences a mental illness.<sup>3-6</sup> Children who grow up with a parent with mental health problems have an increased risk of developing physical and mental disorders. They may also develop other types of problems (eg, educational, social). This is owing to genetic, environmental, and psychosocial factors.<sup>5,7</sup> Parents with mental health problems may sometimes have difficulties providing adequate emotional support.<sup>8</sup> They may face lower household income,<sup>9</sup> food insecurity, and housing issues,<sup>8,10-12</sup> which can all impact children's well-being.

Family-focused interventions, aiming at supporting parenting or (additionally) directly supporting children to prevent them from adverse impacts, have demonstrated significant positive outcomes in clinical studies. One example is the "Let's Talk about

Children Service Model,"<sup>13</sup> which connects relevant stakeholders with families and their social networks to support children's everyday life. Nevertheless, effect sizes of these outcomes are small to medium.<sup>14-17</sup> Given that the resources are scarce, decision-makers need economic analyses alongside effectiveness evidence to identify the best options in using available resources. Yet, comprehensive economic evaluations on family-focused interventions when a parent has a mental disorder are rare and mostly limited to the perinatal period.<sup>18-21</sup> The lack of studies calls for more health economic research, particularly closing the economic knowledge gap in interventions addressing families with children beyond the perinatal period.

Several challenges exist regarding robust economic evaluations in this field. Mental health problems, in general, impact sectors outside healthcare, the so-called intersectoral costs and benefits, which may be challenging to capture adequately.<sup>22</sup>

Additionally, interventions addressing families with parental mental health problems to prevent adverse child outcomes often fulfill the definition of complex interventions.<sup>23</sup> Recent frameworks for evaluating complex interventions have pointed out the

challenge of selecting appropriate outcome measures and choosing an adequate type of economic evaluation.<sup>23</sup>

Furthermore, in the case of early interventions, children of parents with a mental health problem are not necessarily ill themselves. They may receive types of support that standard resource use measurement tools may not include. Support for parents might go beyond what is usually part of the treatment for patients who are mentally ill (eg, help in parenting skills, support on how to talk to the children about their mental illness). Furthermore, the core client may be the family system rather than an individual. These characteristics challenge the calculation of costs in economic evaluations regarding the appropriate perspective and the type of costs to include. For example, it may be a success if parents are motivated to use childcare as part of their support, although this is at the same time increasing resource use and thus costs.

The outcomes of such interventions may also be unique. Even if their key aim is to prevent adverse impacts in children, parents may also benefit from these interventions, and the outcomes can be diverse and go beyond health and health-related quality of life (HRQoL). Standard outcome measures (eg, quality-adjusted life-years [QALYs]) may not adequately capture them because of the limited number of outcome dimensions they entail.

Previous methodological work for example, the PECUNIA project,<sup>24</sup> has not explicitly addressed methodological issues for such interventions. As a first step in designing an economic evaluation, this article aims to determine the spectrum of adverse effects of parental mental health problems in children and the potential economic consequences on an individual and societal level. The results may subsequently serve as a basis and a methodological framework for designing economic evaluations of interventions, which aim to reduce adverse impacts of parental mental health problems with complex interventions.<sup>23,24</sup>

## Methods

### Impact Inventory

We can illustrate the adverse consequences of parental mental illness in an impact inventory.<sup>25</sup> The impact inventory is a generic visualization (a simplified model), demonstrating the multiple consequences of parental mental health problems for both an individual child and the society and the timeframes in which they occur. It furthermore demonstrates the economic impact by showing how public sectors may be affected in terms of costs and what types of private costs may occur for the individual child. The impact inventory provides an orientation on the types of costs and outcomes that economists may have to address in an economic evaluation and on the economic evaluation type, perspective, and time horizon that may be the most appropriate. Thus, it can serve as an analytical framework for identifying critical methodological elements when conducting economic evaluations on interventions for families in which a parent has a mental illness.

The impact inventory focuses on impacts in children  $\geq 4$  years of age. We excluded the perinatal period and age groups  $< 4$  because characteristics of interventions for families with children in this developmental period and thus economic evaluations can substantially differ from interventions addressing families with older children. For example, measuring outcomes in newborns differs from measuring outcomes in older children. Furthermore, economic evaluations addressing interventions for families with older children are generally underresearched, and methodological guidance is missing.<sup>26</sup>

### Data Sources

We conducted a systemic literature search to identify children's consequences of parental mental illness. We selected all empirical studies that measured any adverse impact of parental mental health problems on children  $\geq 4$  years, including long-term difficulties in adulthood. (Cost-)effectiveness results of interventions to reduce the adverse events were beyond the scope of this study. The search strategy is available in the Appendix in Supplemental Materials found at <https://doi.org/10.1016/j.jval.2022.11.016>.

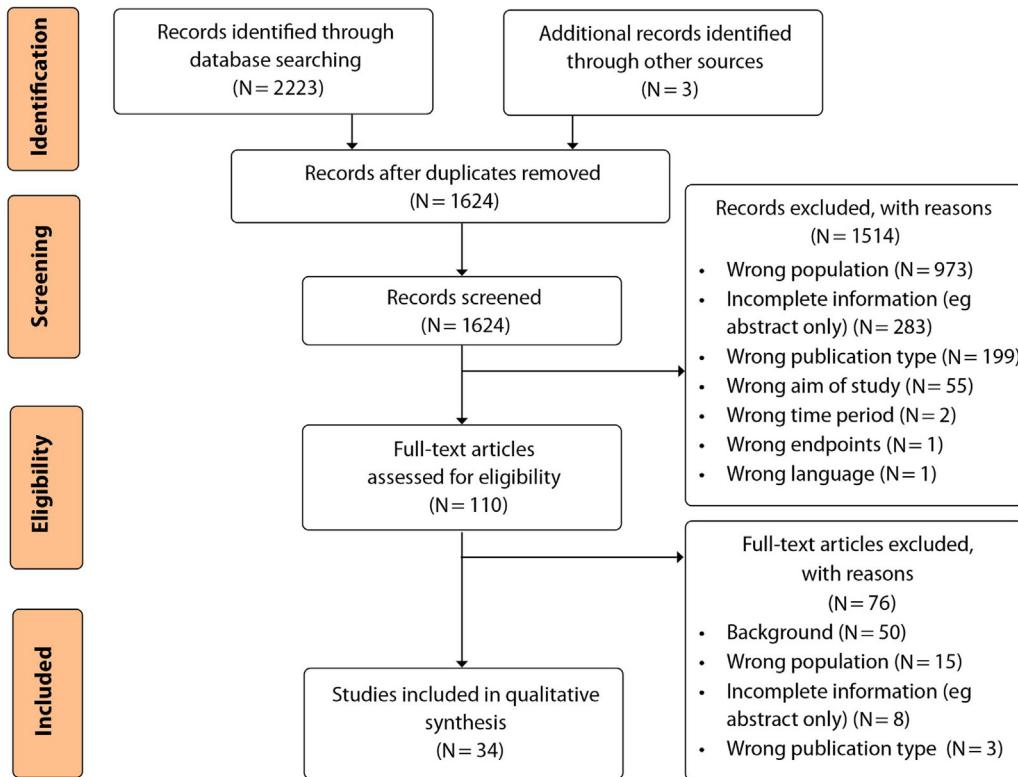
**Table 1** summarizes the inclusion and exclusion criteria for the selection of studies. Two researchers (CS, LH) independently screened the references. From 1624 hits overall, 110 publications were eligible for full-text screening from which we selected 34 publications<sup>8,10-12,20,27-55</sup> for populating the impact inventory (Fig. 1).

### Data Analysis

We first clustered the spectrum of consequences from parental mental health problems based on the identified empirical literature. We predefined 2 categories: (1) adverse effects for children at the individual level and (2) for the society at the mesolevel (the family and social environment) and macrolevel (the general public). According to the empirical data, we inductively clustered the effects into further subcategories within those categories. We aimed to illustrate the variety and types of potential adverse consequences rather than their magnitude or the proportion of children that experience adverse outcomes. Next, we derived types of economic costs from the effects described by analyzing the kinds of support that will be required to address the adverse consequences (eg, mental healthcare, monetary transfers). We then hypothesized the private types of costs that may result for the children individually and public expenses that may occur in different types of public sectors.

**Table 1.** Inclusion criteria.

Category	Definition
Population	Children or adolescents of parents with a mental illness aged $\geq 4$ years and their parents Mental illnesses include all mental and behavioral disorders (F00-F99), for example, affective disorders, schizophrenia, and psychosis, with or without substance misuse
Intervention/comparator	Not applicable
Outcomes	All types of adverse consequences (health and nonhealth) from parental mental illness for children (short-term and long-term)
Study design(s)	Empirical studies measuring adverse child outcomes, no restriction on study design (eg, population-based cohort studies, cross-sectional studies, case-control studies, and national surveys)
Language	English or German
Type of publication	Journal articles and research reports
Search period	2010 to May 2021

**Figure 1.** Flow chart of study selection (PRISMA diagram) for the impact inventory.

## Results

Figure 2 illustrates the impact inventory and provides examples for each element. We identified impacts at the individual and societal levels. The inductive analysis revealed 3 different impact categories at the individual level: (1) mental and physical health impact, (2) impact on social functioning, and (3) socioeconomic impact.

Concerning economic consequences, in addition to individual private costs, we identified the following public sectors that may incur costs: (1) healthcare, (2) social care, (3) education, and (4) criminal justice.

### Individual Mental and Physical Health Impacts

#### Short-term health impact

Regarding mental health, children's exposure to parental mental health problems increases the risk of behavioral difficulties and conduct disorders.<sup>28,30-32</sup> Feelings of being left alone, devalued, excluded by others, and loss of sense of self have been described as common.<sup>28</sup> Social or self-isolation can be further consequences, reinforcing the intergenerational cycle of mental illness.<sup>28</sup> Additionally, children face an increased risk of self-harm and suicide ideation.<sup>33</sup>

Studies have shown that eating disorders,<sup>12</sup> such as obesity<sup>34</sup> that can lead to nutritional issues,<sup>8,12</sup> are more prevalent in children with a parent with a mental health problem compared with children without. Further observed health-related issues in children are sleeplessness,<sup>11</sup> addictive behavior triggered by stress (eg, internet addiction),<sup>35,36</sup> lower visual memory performance,<sup>54</sup> and reduced oral health.<sup>37</sup> Another study has shown that these

children are more likely to grow up in smoking households and are therefore more likely to be exposed to secondhand smoke.<sup>38</sup> Some evidence suggests that children are at an increased risk of injuries.<sup>39</sup>

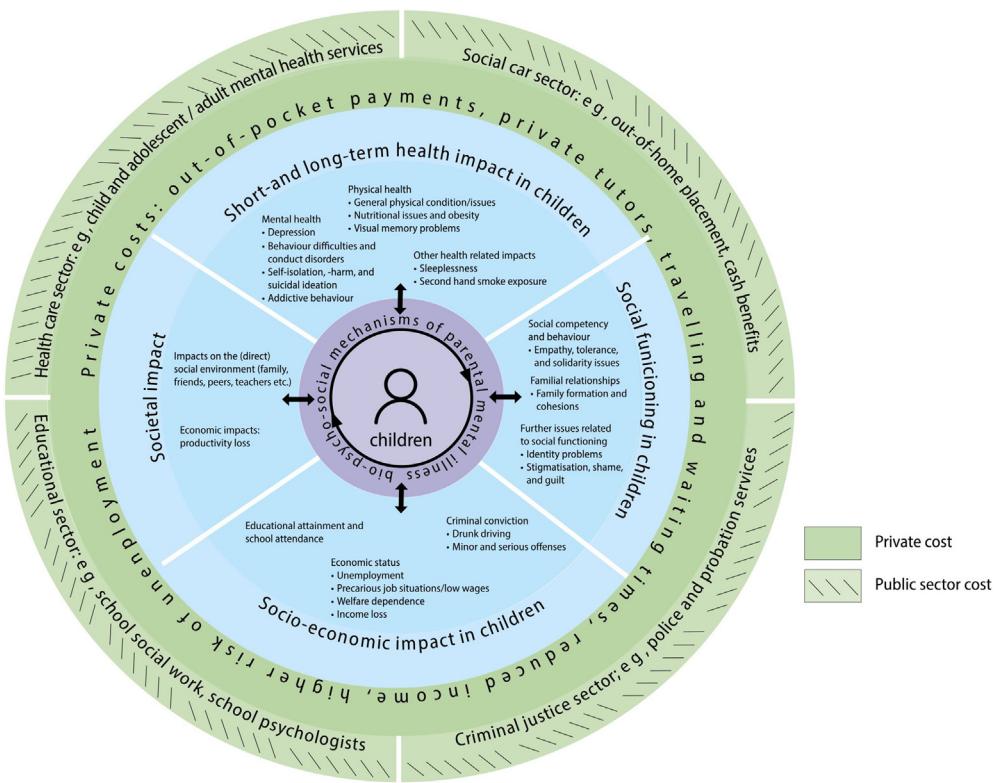
#### Long-term health impact

Adverse health effects, but also other unfavorable consequences from parental mental illness (described below) experienced in childhood, can affect the mental health, functioning, and physical health on the path to adulthood. Exposure to parental illness in childhood may also contribute to psychological diseases and issues among the middle-aged and elderly, such as depression,<sup>29</sup> anxiety disorder, self-harming behavior, or unfavorable physical conditions in later life, such as migraine, sleep problems,<sup>28</sup> or an increased risk of being obese.<sup>34</sup>

### Individual Impact on Social Functioning

Some children may experience adverse effects regarding social competency, which can influence the development of empathy, solidarity, and tolerance.<sup>28</sup> Further potential consequences include impaired social relationships and limited social integration in later life.<sup>28,44</sup> Some sources have identified identity issues, such as children developing an ambivalence between self-responsibility, the social self (how they perceive themselves in relation to others), and responsibility for the parent or others in adulthood. Children can develop a pathological form of "helper syndrome" in later life.<sup>28,44</sup>

Additionally, children often experience guilt and shame<sup>40,41</sup> because of the (perceived) societal stigmatisation<sup>28,42,43</sup> of (parental) mental illness. These experiences and perceptions

**Figure 2.** Impact inventory.

increase the risk of developing internalizing or externalizing problems.<sup>40</sup> Antisocial behavior, conduct problems,<sup>28,30–32</sup> and social isolation<sup>28</sup> are more prevalent in these children than in children who do not grow up with a parent with mental health problems. Reduced self-esteem, (perceived) stigmatization, shame, and feeling guilty because of a parental mental health problem can influence help-seeking behavior<sup>53</sup> and extend into adulthood and influence social functioning later in life.<sup>28,43,44</sup>

Another observation concerns social and familial relationships. Children may experience difficulties establishing long-lasting partnerships in adulthood, and family cohesion can be more fragile.<sup>11,28,29</sup> Nevertheless, that does not mean they cannot have functioning partnerships or marriages.<sup>45</sup> Additionally, some studies indicate that they are less likely to have their own children because of worries of transgenerational transmission of mental illnesses and the fear that they will not be a good enough parent. Nevertheless, they desire to have children.<sup>28,46</sup>

### Individual Socioeconomic Impact

The health adversities experienced by the children can directly influence school attendance<sup>47</sup> and educational attainment<sup>28,29</sup> in the short-term. In the long run, educational attainment is not only a protective factor for physical and mental health, but the academic status also drives individual and societal economic impacts.<sup>20,30</sup> As adults, these children are more likely to experience unemployment, lower wages, precarious job situations, welfare dependence and dependence on public programs, and a poor individual economic status in adulthood.<sup>10,29,30,48</sup> Because these children often care for their sick parents from childhood into adulthood, self-realization is limited, and subsequent income losses may occur in the long-term.<sup>49</sup> Some studies described that

parental mental health problems might lead to criminal activities during adolescence, such as drunk driving and serious and minor offenses.<sup>27,50</sup>

### Societal Impact

The impacts described at the individual level possibly affect the children's social environment (eg, extended family, relatives, friends, and colleagues) and entail medium-term and long-term consequences at a societal level. Firstly, the risk of self-harm and suicide ideation<sup>33</sup> may indirectly affect relatives, friends, and other people in the immediate social environment.

Other impacts on the societal level include productivity loss; for example, because of time spent in treatment and acute service (which is often associated with increased unemployment rates, sick leave, and early retirement).<sup>31,45,51,52,55</sup>

### Economic Consequences

#### Private costs for individuals and families

The adverse (health) consequences in children can result in costs at the individual or family level in the form of private costs at different stages in children's life. These may include out-of-pocket payments, including copayments for treatment in child and adolescent or adult (mental) healthcare, costs for private tutors compensating for reduced school attendance, or traveling and waiting times for treatments. Additional private costs can arise in the long run in the form of reduced income.

#### Public sector costs at the societal level

Regarding affected public sectors at the societal level, the impact dimensions that have been identified above mean that costs can firstly occur in the healthcare sector. Examples are costs

for using child and adolescent (mental) healthcare services or prescription drugs to treat (mental) health problems in children and costs for using adult (mental) healthcare in case of difficulties in adulthood. Second, costs can occur in the social care sector.<sup>31,45,51,52</sup> These include costs for out-of-home placements and coordination of these placements (eg, youth welfare office), vocational services, housing support, and cash benefits (eg, unemployment benefits, early retirement pensions). Furthermore, costs may occur in the educational sector to address conduct problems, antisocial behavior, social isolation, or school absenteeism (eg, school social work, school psychologists, and publicly funded support lessons). Finally, costs in the criminal justice sector may arise in the form of costs for police service, prison, probation service, and so on in case of a criminal conviction.

## Discussion

Our results demonstrate that parental mental health problems can result in a broad variety of consequences for children individually and at the societal level. The most frequently mentioned adversities were negative health impacts, and studies most often identified different forms of mental health issues or risk factors for mental illness in childhood or adulthood. Nevertheless, parental mental illness can also affect the child's physical health (eg, obesity). Beyond health, data showed several consequences on social functioning and socioeconomic disadvantages in later life.

These outcomes result in economic impacts, such as an increased need for mental healthcare. Adverse effects can occur early, on the path to or in adulthood. Regarding public costs, some of the impacts identified fall within the health sector's responsibility. Yet, a large number of these affect other public sectors. One of the few existing costing studies, which looked at costs incurred by children of parents with a mental illness, demonstrated that about 30% of the costs were incurred outside healthcare (eg, child and youth welfare, education). The use of treatment and support was not limited to those children who were already diagnosed of a mental illness.<sup>56</sup> Additionally, costs can occur privately because of copayments for treatment. If preventive programs are successful, they do not just avoid costs in (mental) healthcare but also in other public funding realms, and individuals may face a lower private cost burden.

In line with current methodological research,<sup>22,24,57,58</sup> our results therefore indicate that researchers need to consider intersectoral costs and benefits in economic evaluations on interventions related to parental mental health problems. In particular, costs and benefits outside the healthcare system (eg, costs in the education and criminal justice sector) are relevant. A recently completed systematic review on existing economic evaluations,<sup>26</sup> which yielded 2 cost-effectiveness studies and 1 cost-utility study,<sup>59-61</sup> suggests that there may be gaps in covering the full range of sectors and costs. It is therefore important to choose an adequate perspective in the economic evaluation. Our results suggest that a societal perspective generally seems to be the method of choice. Nevertheless, because costs can accrue in different sectors, adopting multiple perspectives rather than an aggregate societal perspective will be necessary, detecting on whom the costs or savings fall. If the perspective is predefined by the study funder, the researchers might at least explain whether there are costs and consequences beyond those included in the study.

In addition to addressing all public sectors affected, researchers of future studies, in particular, need to ask if private costs for children and their families (eg, [co]payments for treatment and services) and informal care are relevant cost categories to be

covered. The latter can be a challenge because informal care provided by young carers replaces leisure time or education rather than paid work, which may require specific valuation methods.<sup>62</sup> Nevertheless, careful considerations are needed to avoid double-counting of costs. For example, unemployment may be addressed as a cost or in the assessment of well-being on the outcome side.

Research from related fields suggests that capturing the full scope of costs from interventions that address families with parental mental illness can be more challenging than evaluating standard healthcare interventions. Costs beyond healthcare play an important role and there are fewer routine data sources available (eg, for assessing unit costs) to capture them adequately, and self-reported resource use may be biased by poor recall accuracy.<sup>63</sup> Usually, the involved organizations have limited staff capacity to support research activities.<sup>64</sup>

In perinatal mental health, Bauer et al<sup>65</sup> demonstrated that the most significant proportion of the total costs of parental perinatal mental health problems (72%) relates to the child. Considering the broad spectrum of adverse impacts in children from our results, this seems to be equally relevant if children are older. Therefore, economic evaluations need to make sure to capture costs and outcomes in children in addition to parents.

Regarding child outcomes, our results demonstrate that family-focused preventive programs may affect children's health in various dimensions but also affect outcomes beyond health (eg, social functioning). Nevertheless, existing studies have usually addressed 1 outcome dimension (eg, parenting quality as a surrogate for the children's well-being measured by the Home Observation for Measurement of the Environment score<sup>59</sup>). Where mental health outcomes were measured, they addressed only 1 mental health dimension (eg, parent-rated child behavior problems measured by the Eysberg Child Behavior Scale<sup>60</sup>).

QALYs, which have also been used,<sup>61</sup> may indirectly capture parts of the health impacts illustrated in Figure 2, because health detriments likely influence QoL. Nevertheless, similar to earlier discussions on QALYs,<sup>66</sup> it is unclear to what extent the domains in the EQ-5D that studies used to elicit HRQoL captured the nuances of physical and mental health impacts, social functioning, or the socioeconomic consequences (eg, school attendance) that we have illustrated in the inventory. Additionally, to date, there is no guidance available on how to measure HRQoL in children appropriately.<sup>67</sup> Furthermore, although the number of child-specific value sets for valuing generic health states has increased, many questions remain. It is unclear whether to ask adults or children and whether the children's age affects these values.<sup>67</sup> In our case, using such value sets raises further questions, because family-oriented programs in mental health can affect HRQoL in children and parents. Yet, health state valuation differs between children and adults<sup>68</sup> and QALYs derived from them may not be comparable.<sup>67</sup>

It seems worth considering alternative outcome measurement instruments going beyond HRQoL, such as the Oxford CAPabilities questionnaire-Mental Health<sup>69,70</sup> and developing them further for use in children. An example for capturing outcomes beyond HRQoL in children and parents is a framework developed by "What works for Children's Social Care,"<sup>71</sup> which includes child and family rights outcomes in addition to child, parental, carer, and family outcomes, as well as organizational factors.<sup>63</sup> Nevertheless, in line with researchers in social care economics,<sup>64,72</sup> further research is required on standardization and thresholds for outcomes to make interventions more comparable.<sup>63,72</sup>

Following current standards in economic evaluation, existing studies used cost-effectiveness or cost-utility analyses.<sup>59-61</sup> In the former, authors presented results as costs per change in the

effectiveness scale chosen (eg, costs per Home Observation for Measurement of the Environment score improvement). A discussion on the informative value of such ratios for decision-makers is warranted because they limit comparability with other interventions. The absence of thresholds for such ratios makes conclusions about the interventions' value for money difficult. Additionally, the restriction to 1 outcome measure to present a single cost-effectiveness ratio forces researchers to ignore other possibly relevant outcomes. In line with the recent recommendations on the economic evaluation of complex interventions<sup>23</sup> and some guidelines (eg, National Institute for Health and Clinical Excellence<sup>73</sup> and Canadian Agency for Drugs and Technologies in Health<sup>74</sup>), cost-consequence analysis seems to be more promising in considering the complexity of outcomes. Nevertheless, this study type has its own limitations (eg, risk of outcome cherry-picking, limited comparability).

Our results further showed that impacts of parental mental illness can occur later in life with substantial individual and societal economic consequences. Economic evaluations need to capture programs' long-term impact on socioeconomic dimensions (eg, employment) or productivity. The existing evaluations have mainly used a short-time horizon without stating a rationale<sup>59,60</sup> and may not have covered the full magnitude of costs and outcomes. A review of economic evaluations in the perinatal field has demonstrated similar shortcomings.<sup>21</sup> In contrast, others<sup>75</sup> have shown that many mental health promotion or illness prevention interventions are good value for money if they address a broad spectrum of costs and outcomes and apply a long-term time horizon. Studies may draw on modeling methods, such as done by Gardner et al.<sup>60</sup> They project the potential longer-term savings in addition to presenting short-term cost-effectiveness results based on trial data. Following examples in other fields (eg, panel studies),<sup>76</sup> robust primary data on long-term impacts are needed. Collecting primary data on long-term consequences, in a representative sample of adult children who grew up with a mentally ill parent compared with adult children who did not, may be another approach.

Many of the challenges we addressed (eg, capturing the full scope of costs and outcomes beyond health-related effects, spillover costs, and effects on family members) have been described in related fields, such as general parenting interventions or Children's Social Care interventions. Mutual learning may be possible in finding ways to overcome them.

Our article has some limitations. First, we might have missed studies with our search strategy and may not have captured the full range of consequences of parental mental illness for children. We were limited to including sources in English and German. The search period was 2010 onwards.

Because the aim was to illustrate the types of adverse consequences rather than their magnitude, we did not assess the quality of the studies. Therefore, some associations between parental mental illness and child outcomes may be uncertain. Because we focused on illustrating child impacts, we did not depict how each impact category may have feedback effects on the parents. Furthermore, not all children develop problems because of parental mental illness.<sup>77</sup> We did not present proportions of children that (do not) experience adverse consequences.

## Conclusions

In this article, we presented an overview of the spectrum of adverse impacts of parental mental health problems on children and the economic consequences that may occur as a result. We explored the methodological implications for conducting an

economic evaluation in this field. The challenges and ways to overcome them are likely generalizable across jurisdictions because they primarily stem from the nature of parental mental illness and the characteristics of family-focused interventions (eg, need to measure outcomes in both parents and children).

Economic evaluations need to be designed in accordance with the complex nature of parental mental illness and its consequences for children and society. If we do not adequately address (long-term) consequences of parental mental illness in children, we may underestimate cost-effectiveness and discriminate respective interventions. Current standard methods, such as cost-effectiveness analyses, have limited flexibility to capture the complete picture of costs and benefits (eg, because of their restriction to a single outcome measure), resulting in a risk of misleading study results for decision-makers.

More economic evaluations on already existing programs in family mental health are needed, piloting different methodological approaches. One methodological priority is to develop standards for measuring outcomes in children. Our overview may serve as an analytical framework for the design of economic evaluations, particularly regarding the study type, perspective, time horizon, cost, and outcome categories. We can learn from related fields facing similar challenges, such as social care economics.

Obtaining more robust evidence on the value for money will better support decision-makers in resource allocation and in making the economic case for the prevention of adverse child outcomes related to parental mental health problems.

## Supplemental Material

Supplementary data associated with this article can be found in the online version at <https://doi.org/10.1016/j.jval.2022.11.016>.

## Article and Author Information

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