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Family caregivers' burden in inflammatory bowel diseases: An integrative review

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Abstract:

Inflammatory bowel disease (IBD), including Crohn's and ulcerative colitis diseases, is characterized by clinical periods of remission and relapse. Excessive care stress can have long-term negative physical and psychological consequences not only for caregivers but also for the recipients of care. This integrative review aims to identify, describe, and synthesize the results of current available research focused on the burdens of IBDs on family caregiver. An integrative review was performed using Whittemore and Knafl methodology. A systematic search of electronic databases including Web of Science, PubMed, Embase, and Scopus from January 2000 to October 2019 was conducted. Articles were included if published in English and focus on IBD burden on family caregivers. Of 730 records, 16 articles with quantitative, qualitative, and Q methodology study designs were eventually included in the review. The synthesis of these articles led to the identification of four key types of effects: biopsychosocial, daily life activities, physical health, and financial. The chronic and relapsing nature of IBD exposes family caregivers to considerable risk. Thus, the care burden of IBD patients' caregivers needs to be evaluated continuously and relieved through family-centered interventions.

Keywords:

Burden of disease, caregivers, family, inflammatory bowel diseases

Introduction

Inflammatory bowel disease (IBD), including Crohn's and ulcerative colitis diseases, is characterized by clinical periods of remission and relapse. The frequent need for health-care services, multiple hospitalizations, drug effects, surgery, stoma formation, and the fear of being a burden are a few of the concerns commonly associated with IBD, and these can have many adverse effects on the patient's quality of life.[1] The increase in health-care and psychosocial needs related to IBD can render patients dependent on their caregivers to carry out daily activities, administer their medication, drive them to medical visits, and provide emotional, financial, or other forms of support.[2] The family members and friends of IBD patients usually assume the caregiver role, especially when the disease reaches severe stages.

IBD tends to place significant stress on the patient's interpersonal relationships over time.[3] Excessive care stress can have long-term negative physical and psychological consequences not only for caregivers but also for the recipients of care.[4] Zand *et al*. found that over 70% of caregivers of IBD patients experienced reduced performance and productivity in their jobs, and more than 30% of them had to take leaves of absence. Furthermore, over 44% of these caregivers experienced a poor-to-moderate care burden.[5]

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Although different authors have provided different definitions of care burden, most definitions share a focus on the adverse effects of care in various domains (e.g., physical, emotional, social, financial, and spiritual).[6] Studies that have examined the burden of IBD on family caregivers are disjointed. Therefore, this integrative review aims to identify, describe, and synthesize the results of current available research focused on the burdens of IBDs on family caregiver.

Materials and Methods

Search strategy

The Web of Science, PubMed, Embase, and Scopus databases were searched for the period of January 2000 to October 2019. Google Scholar was searched for additional articles. Furthermore, the reference lists provided in all the identified articles were assessed for eligibility, and reviews of burden and caregivers were screened to find additional relevant studies. The search strategy utilized MeSH terms. The general search strategy developed is described in Box 1.

Box 1: Search terms and filter for Web of Science, PubMed, Embase, and Scopus

PubMed: ("Family"[Mesh]) AND "Inflammatory Bowel Diseases"[Mesh] = 449

Scopus: (TITLE-ABS-KEY (("family caregiver" OR "informal caregiver" OR "parental caregiver" OR caregiver OR caregiving OR "parental caregiving")) AND TITLE-ABS-KEY ("inflammatory bowel diseases")) = 92

Web of science: TOPIC: (("family caregiver" OR "informal caregiver" OR "parental caregiver" OR caregiver OR caregiving OR "parental caregiving")) AND TOPIC: (("inflammatory bowel diseases" OR IBD OR "ulcerative colitis" OR crohn* OR "crohn's disease")) = 76

Embase: caregiver AND 'inflammatory bowel disease': ti, ab, kw=113

Inclusion and exclusion criteria

Inclusion criteria were (i) primary focus of the study on IBD burden expression and (ii) qualitative, survey, and Q methodology studies. Exclusion criteria were (i) epidemiological, interventional, and review studies and (ii) having the paper briefly presented at a conference.

Quality assessment

The STROBE checklist was used to assess the quality of survey studies[7] [Appendix 1] and the VAKS checklist, which has been designed and validated based on Lincoln and Guba criteria in Denmark was used to assess qualitative studies[8] [Appendix 2 and Table 1].

Table 1: Reporting quality of studies according to the VAKS and STROBE criteria

Author	Assessment tool	Quality of studies
Vergara *et al.*[10]	VAKS checklist	High
Liu *et al.*[11]	STROBE checklist	Moderate
Gray *et al.*[12]	VAKS Checklist	High
Day *et al.*[13]	STROBE checklist	Moderate
Loga *et al.*[14]	VAKS checklist	High
Parekh *et al.*[15]	STROBE checklist	High
Odell *et al.*[16]	STROBE checklist	Moderate
Guilfoyle *et al.*[17]	STROBE checklist	Moderate
Werner *et al.*[18]	STROBE checklist	Moderate
Jelenova *et al.*[19]	STROBE checklist	Moderate
Lindfred *et al.*[20]	STROBE checklist	High
Greenley *et al.*[21]	STROBE checklist	Moderate
Sin *et al.*[22]	STROBE checklist	High
Magro *et al.*[23]	STROBE checklist	High
Lindström *et al.*[24]	STROBE checklist	High
Plevinsky *et al.*[25]	STROBE checklist	Moderate

Data extraction and synthesis

Whittemore and Knafl[9] five stages of data analysis (problem identification, literature search, data evaluation, data analysis, and presentation) were used to synthesize the data. The researchers repeatedly examined the studies; any themes related to IBD burden on caregivers that were described either descriptively or as percentages were extracted [Table 2]. Regarding the family caregivers' burdens, we categorized the main findings of reviewed studies into four groups: biopsychosocial effects, daily life activities, physical health, and financial effects.

Results

Study characteristics

A total of 730 English papers were extracted from databases; after duplicates were removed, 538 papers were retained.

Their titles and abstracts were reviewed and matched against the specified inclusion and exclusion criteria. After this process, 55 papers were selected to review their full texts. By reviewing the full text of the papers, 39 papers that did not directly refer to the burden of disease or its impact on family caregivers were removed and 16 papers (13 surveys and three qualitative papers) were selected for the final analysis [Figure 1].

Sample and participants characteristics

The number of samples varied from 16 to 106 for qualitative studies and from 38 to 324 for survey studies. Participants' type of relationship with the patient, age, gender, educational level, job status, and marital status were assessed [Table 2].

Family caregivers' burden

After comparing and synthesizing similar themes, the four final themes were classified as biopsychosocial

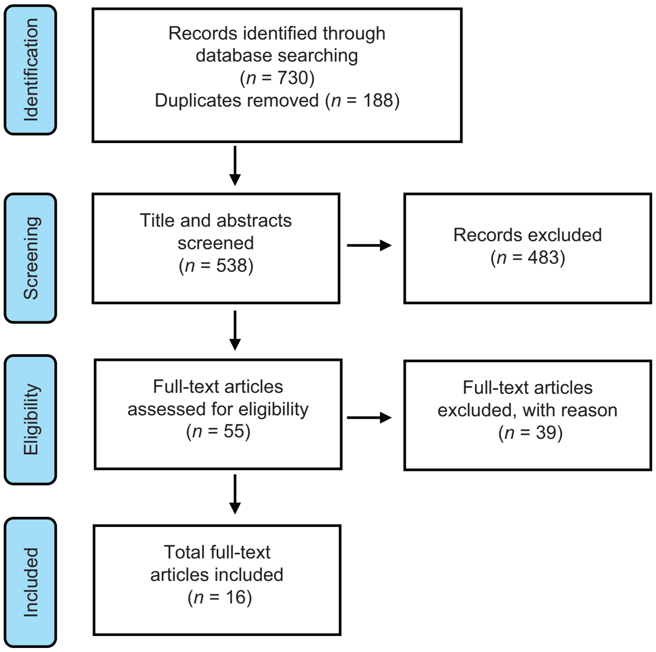

Figure 1: Preferred reporting items for systematic reviews flow diagram

effects, daily life activities, physical health, and financial effects.

Biopsychosocial effects

One of the most significant effects of IBD burden on family caregivers is biopsychosocial effects, as directly stated in all the studies examined. Biopsychosocial effects mentioned in the literature include depression; anxiety; sleep problems; concerns about treatment; trouble commuting; surgery; death; disability at work; weight changes; problems with excretion; concerns about the patient's future life; growth issues; failure to undergo puberty; an unhealthy diet; negative side effects; mood effects; poor nutrition; a lack of patient education; concerns about access to support services (rehabilitation, nutritionist, psychotherapy, and so on); psychiatric problems among family members; impaired social functioning; family conflicts; family breakdowns; impaired communication; social phobia symptoms, exhaustion; and a sense of helplessness.[10-25]

Daily life activities

IBD burden is also known to affect family caregivers' daily activities due to limitations caused by their role as caregiver, over involvement in patient care, scheduling visits to physicians, stopping work to provide patient care, and constraints on daily life and leisure time because of the cost of the disease.[11-13,15,17,20,22,23,25]

Physical health

Caregivers of IBD patients can suffer from burnout, symptoms related to persistent physical fatigue syndrome, energy loss, and high physical stress.[18,20,21]

Financial effects

Finally, caregivers of IBD patients often face financial challenges if they are forced to provide living and treatment costs for the patient.[11,12,14,22,25]

Discussion

This integrative review aims to identify, describe, and synthesize the results of current available research focused on the burdens of IBD on the family caregiver. The health of an IBD patient's caregiver is crucial to the outcomes of the patient. Therefore, the burden of care must be considered when a friend or family member agrees to look after an IBD patient. The excessive burden imposed on caregivers can leave them physically, financially, or otherwise unable to care for the patient, thus ultimately harming rather than helping the patient.[15] The analysis of the selected studies indicated that family caregivers of IBD patients undergo a great deal of stress. Stressors can be categorized into four broad types: psychological, daily activities, physical, and financial health. All four types of stressors affect caregivers' life quality in various ways.

Other studies have examined the care burden associated with chronic diseases like cirrhosis,[4] diabetes,[26] cancer,[27] and heart failure.[28] These studies have shown that caregivers experience psychological, social, and economic stress and that their daily lives are disrupted as a result of providing the patient with care. Caregivers' demographic factors can predict the magnitude of care burden. Factors such as gender, age, role of spouse, income and education level, number of family caregivers, history of mental disease in the family, and social and spiritual support can determine the severity of the care burden that a person experiences.[10,11,14,15,20,23]

Income status stands out as a strong predictor of care burden. Caregivers with a low income or occupational status, or who lack adequate insurance coverage, are affected very strongly by their caregiving duties and tend to experience an intense care burden. On the other hand, those with a high economic status have better access to health care and tend to have more support; therefore, they usually experience a relatively low level of care burden.[15] Bajaj *et al*. examined the care burden of caretakers of patients with cirrhosis and found that financial insecurity caused a psychological burden for caregivers. This burden then contributed to the patient's failure to adhere to their treatment regimen for hepatic encephalopathy.[29] Conversely, McMaster *et al*. showed that caretakers who received social and spiritual support experience less care burden.[30] Studies

Table 2: Family caregivers' characteristics

Author (year); country	Relationship with IBD patient: (parents, Spouse, sibling, and others)	Family caregivers' demographics		Materials and methods	Family caregivers' burden
		Sex (male; female); Total number	Educational level		
Vergara *et al.* (2002); Spain[10]	Mother: 18 (22%) Father: 17 (21%) Spouse: 32 (39%) Son/daughter: 8 (10%) sibling: 6 (8%)	Ratio men/ women: 1.1 Total number: 81	No studies: 14 (17%) Primary studies: 30 (37%) High school: 25 (31%) University: 12 (15%)	Qualitative study Household members were interviewed	Worry about treatment Worry about patient's dying Worry about patient's surgery Worry about patient's inability to work Worry about future normal life Worry about patient's defecation
Liu *et al.* (2018); China[11]	NR	Male: 50 (49.02%) Female: 52 (50.98%) Total number: 102	Basic: 8 (7.84%) High school: 10 (9.8%) College: 76 (74.51%) Graduate: 8 (7.84%)	Survey study Family caregivers completed questionnaires	High level of anxiety High level of depression Role limitations Spend a lot of money
Gray *et al.* (2015); USA[12]	Mother: 14 (87.5%) Father: 2 (12.5%)	Male: 14 (87.5%); Female: 2 (12.5%) Total number: 16	4-year college degree educated or above: 10 (62.5%)	Qualitative study Focus group interviews	High level of anxiety Worry about finances and their ability to secure health insurance and take on financial responsibility in the future Heavily involved in their young adult's IBD care Recognizing when medical care is needed
Day *et al.* (2005); Australia[13]	Parents	NR Total number: 46	NR	Survey study Parents completed a questionnaire	Worry about medicines, growth, puberty, the future, diet, side effects, nutrition, and schooling their children Worry about neglecting other children Restrictions upon the family lifestyle Impact on family quality of life aspects
Loga *et al.* (2012); Bosnia[14]	NR	Male: 27 (54%) Female=23 (46%) Total number: 50	The average number of years of formal: 12 (high school education)	Qualitative study Face-to-face structured interview and using a questionnaire	Concerns about access to support services (medical rehabilitation, nutritionist, psychotherapy, etc.) Mental health problems in the families with IBD Dedicate a large portion of family income to treat Poor quality of life of family caregivers
Parekh *et al.* (2017); USA[15]	Spouse: 81 (50.6) Parent: 36 (22.5%) Child: 27 (16.9%) Sibling: 2 (1.3%) Friend: 2 (1.3%)	Male: 53 (33.1%) Female: 107 (66.9%) Total number: 162	Middle school: 26 (16.0) High school: 88 (54.3) College degree: 40 (24.7)	Survey study Caregivers were asked to complete four separate questionnaires	Mental disorders Poor psychological well-being Depressive symptoms Stop working because of caregiving to the patients Impaired social functioning Poor quality of life of family caregivers
Odell *et al.* (2011); USA[16]	Mother: 89% Father: 9% Other caregiver: 2%	NR Total number: NR	NR	Survey study Families completed questionnaire	Family conflict/dysfunction Disruptive to the family unit
Guilfoyle *et al.* (2012); US[17]	NR	Male: 7 (11.3%) Female: 55 (88.7%) Total number: 62	NR	Survey study Caregivers completed a questionnaire.	Emotional Distress Impairment of Role function Burden of patient care Disrupted communications

Contd...

Table 2: Contd...

Author (year); country	Relationship with IBD patient: (parents, Spouse, sibling, and others)	Family caregivers' demographics		Materials and methods	Family caregivers' burden
		Sex (male; female); Total number	Educational level		
Werner *et al*. (2015); Switzerland[18]	Mother: 125 (54%) Father: 106 (46%)	Male: 106 (46%) Female: 125 (54%) Total number: 231	NR	Survey study to assess the parents' mental health, Symptom Checklist was used.	Experiencing symptoms of depressive disorder Experiencing symptoms of mistrust Anxiety disorder (Agoraphobia) Experiencing symptoms of social phobia
Jelenova *et al*. (2015); Czech[19]	Mother and father	NR Total number: NR	NR	Survey study The parents completed questionnaires	Symptoms of depression Symptoms of anxiety Low scores on the quality of life in the parents
Lindfred *et al*. (2009); Sweden[20]	Mother: 65 (54%) Father: 54 (46%)	NR Total number: 119	NR	Survey study Parents completed a questionnaire	Worry about their children's future health Fear about the side effects of medication Concerns for future schooling, social life and employment Limitations in daily life regarding leisure activities Limitations in daily life regarding extra costs
Greenley *et al*. (2009); USA[21]	Mother: 39 (70%)	NR Total number: 55	College or professional degree: 29 (59%)	Survey study Parents completed a questionnaire	Fatigue and low energy Physical strain Poor quality of life of family caregivers
Sin *et al*. (2015); USA[22]	NR	NR Total number: 150	High school: 10 (6.7) Bachelor: 60 (40.0) Graduate: 60 (40.0)	Survey study Parents completed a questionnaire	Concerns about treatment costs Missed work and Lost wages Transportation costs
Magro *et al*. (2009); Portugal[23]	Spouse: 61% Mother: 19% child career: 6%	Male: 130 (40) Female: 187 (58) Total number: 324	Basic: 87 (26.9) Diploma: 138 (42.6) Bachelor: 6 (1.9) Graduate: 13 (4.0)	Survey study Caregivers were asked how their situation affected	Having time to themselves Impact on the ability to work Impact on some aspects of work function
Lindström *et al*. (2009); Sweden[24]	Mother: 21 (55.3%) Father: 17 (44.7%)	Male: 17 (44.7%) Female: 21 (55.3%) Total number: 38	Basic: 10.5% high school: 57.9% University: 31.6%	Survey study Parents completed a questionnaire	Burnout symptoms Emotional fatigue Permanent physical exhaustion syndrome
Plevinsky *et al*. (2018); USA[25]	Biological mother: 41 (80.4%) Biological father: 9 (17.6%)	Male: 9 (17.6%) Female: 42 (82.4%) Total number: 51	NR	Survey study Parents completed a questionnaire	Feeling helpless over my child's condition Feeling uncertain about the future Illness-related parenting stress Difficulty sleeping Having money/financial Troubles

IBD=Inflammatory bowel disease, NR=Not Reported

have shown that interventions intended to enhance the well-being of patients and their caregivers reduce the burden of disease on the caregiver. For instance, Milbury *et al*. examined the effects of a 12-session yoga program focusing on respiratory exercises, relaxed movements, and guided relaxation that was designed for patients with high-grade glioma and their caregivers. The results showed a statistically significant decrease in patients' sleep disturbance and improvements in patients' and caregivers' quality of life.[31]

Excessive care stress can have long-term negative physical and psychological consequences for family caregivers. It is vital to evaluate the care burden of IBD patients' caregivers continuously and mitigate it through family-centered interventions.

Conclusions

Ultimately, the chronic and relapsing nature of IBD exposes family caregivers to considerable risk. Hence, they require psychological support to protect against the adverse effects of stressors and to adapt to the disease and effectively manage the problems that come with it. Moreover, patient caregivers should modify any unrealistic expectations and take advantage of supportive services and learn problem-solving skills.

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Conflicts of interest

There are no conflicts of interest.

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Appendix 1: Reporting quality of studies according to the STROBE criteria

Item	Item No	Author (year)												
		Liu *et al.* (2018)	Day *et al.* (2005)	Parekh *et al.* (2017)	Odell *et al.* (2011)	Guilfoyle *et al.* (2012)	Werner *et al.* (2015)	Jelenova *et al.* (2015)	Lindfred *et al.* (2009)	Greenley *et al.* (2009)	Sin *et al.* (2015)	Magro *et al.* (2009)	Lindström *et al.* (2009)	Plevinsky *et al.* (2018)
Title and abstract	1(a)	1	0	0	0	0	0	1	1	0	1	1	0	0
	1(b)	1	1	1	1	1	1	1	1	1	1	1	1	1
Introduction														
Background	2	1	1	1	1	1	1	1	1	1	1	1	1	1
Objectives	3	1	1	1	0	1	0	0	1	1	1	1	0	1
Methods														
Study design	4	1	0	1	1	1	1	1	1	1	1	1	1	1
Setting	5	0	0	0	1	1	1	0	1	1	1	0	1	1
Participants	6(a)	1	0	1	1	1	1	0	1	1	1	1	1	1
	6(b)	NA	NA	0	0	NA	0	1	1	1	1	1	NA	NA
Variables	7	0	0	1	1	1	0	0	1	0	1	1	1	1
Data sources	8	1	1	1	1	1	1	1	1	1	1	1	1	1
Bias	9	0	0	0	0	1	0	0	0	0	1	0	0	0
Study size	10	1	1	1	1	1	1	0	1	1	1	1	1	1
Quantitative variables	11	0	1	1	1	1	1	1	1	0	1	1	1	1
Statistical methods	12(a)	1	1	1	1	1	1	1	1	1	1	1	1	1
	12(b)	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA
	12(c)	0	0	1	1	0	NA	NA	1	1	0	1	NA	0
	12(d)	NA	NA	NA	NA	NA	NA	1	NA	NA	NA	NA	NA	NA
	12(e)	0	0	0	0	0	0	0	0	0	0	0	0	0
Results														
Participants	13(a)	0	0	0	0	0	0	0	0	0	0	0	0	0
	13(b)	0	NA	NA	NA	0	1	NA	NA	NA	1	NA	NA	NA
	13(c)	NA	NA	NA	NA	NA	NA	NA	NA	NA	1	NA	NA	0
Descriptive data	14(a)	1	1	1	0	0	0	0	1	1	1	1	1	1
	14(b)	0	1	1	1	1	1	0	0	1	1	0	1	0
	14(c)	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA
Outcome data	15	1	1	1	1	1	1	1	1	1	1	1	1	1
Main results	16(a)	1	1	1	1	1	1	1	1	0	1	1	1	1
	16(b)	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA
	16(c)	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA
Other analyses	17	NA	NA	NA	NA	NA	NA	NA	NA	NA	1	NA	NA	NA
Discussion														
Key results	18	1	1	1	1	1	1	1	1	1	1	1	1	1
Limitations	19	1	1	1	0	1	1	0	1	1	1	0	1	1
Interpretation	20	1	1	1	1	1	1	1	0	1	1	1	1	1
Generalisability	21	0	1	1	1	0	1	1	1	1	1	1	0	1

Contd...

Appendix 1: Contd...

Item	Item No	Author (year)												
		Liu *et al.* (2018)	Day *et al.* (2005)	Parekh *et al.* (2017)	Odell *et al.* (2011)	Guilfoyle *et al.* (2012)	Werner *et al.* (2015)	Jelenova *et al.* (2015)	Lindfred *et al.* (2009)	Greenley *et al.* (2009)	Sin *et al.* (2015)	Magro *et al.* (2009)	Lindström *et al.* (2009)	Plevinsky *et al.* (2018)
Funding	22	1	1	1	1	1	0	1	1	0	1	1	1	1
Total score		16/26	16/25	20/26	18/26	19/26	17/26	15/26	21/26	18/26	26/29	20/26	18/24	19/26
Percentage		61.5	64	78	69	73	66	58	81	69	90	78	75	73
Quality of study		M	M	H	M	M	M	M	H	M	H	H	H	M

NA=Not available, M=Moderate, H=High

Appendix 2: Reporting quality of studies according to the VAKS criteria (Qualitative study)

Criteria	Author (year)		
	Vergara *et al.* (2002)	Gray *et al.* (2015)	Loga *et al.* (2012)
Formal requirements			
Background of the study is described through the existing literature	3	3	3
It appears why the study is relevant	4	4	4
It is described how demands to informed consent, voluntariness, and anonymization of data have been met (Helsinki Declaration or Nursing Research in the Nordic Countries)	4	4	4
It is described if there are relevant approvals (e.g., The Data Agency Board, Ethical Committee)	4	4	4
The researcher has described whether the study can affect the informants	2	2	3
The researcher has described what will be done if the study affects the participants	2	2	2
Credibility			
The purpose is described clearly	4	4	4
The method is described	4	3	3
Arguments for choice of method have been made	3	3	3
The method suits the purpose	4	3	3
There is a description of how data were registered (digitally, by video, notes, field notes, etc.)	3	3	3
Triangulation has been applied	2	3	4
The research process is described	3	3	4
Transferability			
Selection of informants or sources is described	3	4	4
There is a description of the informants	3	3	3
It is argued why these informants are selected	3	3	3
The context (place and connection of research) is described	4	3	4
The relationship between the researcher (s) and the context (in which the research takes place) as well as the informants	3	3	3
Dependability			
A logical connection between data and themes developed by the researcher is described	3	3	4
The process of analysis is described	4	4	4
There is a clear description of the results	3	3	4
The findings are credible	3	3	3
Any quotations are reasonable/supporting the interpretation	3	3	3
There is agreement between the findings of the study and the conclusions	3	3	3
Confirmability			
The researcher has described his background and perceptions or pre-understanding	2	3	3
There are references to theory/theorists (clear who has inspired the analysis)	2	2	3
There is a description of whether themes emerged from data or if they were formulated in advance	3	3	4
It is described who conducted the study	3	3	4
It is described how the researcher participated in the process of analysis	3	3	4
The researcher has described whether his position is important in relation to the findings	2	3	2
Total score	92/5=18.5	91/5=18.2	100/5=20

Evaluation: Totally disagree (1), disagree (2), agree (3), totally agree (4), Total score/number of criteria (5). Score: Recommended (≥15) Recommended with reservations (≥10 <15) not recommended (<10)