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# Umbrella review of family-focused care interventions supporting families where a family member has a long-term condition

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## Abstract

**Aim:** The aim of this study was to summarize reviews of family-focused care interventions that support families with a family member with a long-term condition across the life course.

**Design:** Umbrella review.

**Data sources:** Medline (1946–2019), Cochrane Database of Systematic Reviews (2019), Database of Abstracts of Reviews of Effect and EMBASE (1947–2019), CINAHL (1981–2019), Health Technology Assessment Database (2019) and PsycInfo (1806–2019).

**Review Methods:** All authors independently undertook title/abstract screening, data extraction and quality appraisal on a cluster of papers, working in groups of two or three to reach a consensus. The AMSTAR tool was used to appraise the quality of the studies and descriptive syntheses were undertaken.

**Results:** Fifteen reviews met the selection criteria. Overall family-focused care and associated terms were poorly defined. Typically interventions were educational or psychological therapy/counselling with the goal of empowering individuals to manage their condition. There is some evidence that family-focused care interventions can improve clinical/biological health measures and self-care outcomes such as treatment adherence. Multicomponent psychosocial interventions that include cognitive-behavioural therapy, skills training, education and support and are focused on wider family members appear to improve family relationships and marital functioning.

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**Conclusion:** Long-term conditions have an impact on individual and family health and well-being, yet the impact of family-focused care interventions on family outcomes was overall inconclusive. A better understanding of how family-focused care interventions improve the health and well-being of individuals and their families is needed to promote the inclusion of family-focused care into practice.

**Impact:** Supporting people with a long-term condition is a key health and social care priority. Family-focused care interventions have potential to improve the health and well-being of individuals and families, but there is a need to evaluate their clinical and cost-effectiveness. The findings from this review could be used by funding bodies when commissioning research for long-term conditions.

#### KEYWORDS

family nursing, family-focused care, life course, long-term conditions, umbrella review

## 1 | INTRODUCTION

Supporting people with a long-term condition (LTC) is a key health and social care priority across developed economies. Approximately 15 million people in England live with an LTC, with the number of people with multiple conditions predicted to rise from 1.8-2.9 million by 2020 (Department of Health, 2012). Although the mortality for individuals with LTCs varies between countries, LTCs are responsible for an estimated 71% of deaths globally (Global Burden of Disease, 2016; World Health Organisation, 2017). People with LTCs have enduring mental and/or physical health problems that result in greater use of primary, secondary and social care services (Salisbury, Johnson, Purdy, Valderas, & Montgomery, 2011), poorer health outcomes (Fortin, Soubhi, Hudon, Bayliss, & Akker, 2007) and negative perceptions of well-being compared with people without an LTC (Årestedt, Benzein, & Persson, 2015; Roddis, Holloway, Bond, & Galvin, 2016). LTCs have a significant global economic impact, for example, China, India and the UK have projected losses in national income of \$558 billion, \$237 billion and \$33 billion, respectively, as a result of heart disease, stroke and diabetes (Global Burden of Disease, 2016).

The challenges for both the individual and the family include illness-specific demands such as maintaining treatment and care regimens, social and financial constraints and maintaining family relationships (Roth, Perkins, Wadley, Temple, & Haley, 2009; Smith, Cheater, & Bekker, 2015), increasing as the number of coexisting conditions increases (Wallace et al., 2015). Furthermore, international evidence indicates that LTCs in early life can affect individuals' health and well-being across the life course (Ben-Shlomo & Kuh, 2002; Jacob, Baird, Barker, Cooper, & Hanson, 2017). Establishing what family-focused care interventions have been evaluated and if they are clinically and cost-effective could support organizations and commissioners when deciding future services. We report an international review of reviews, known as an 'umbrella' review that summarizes the findings of reviews of family-focused care interventions in

supporting families, across the life course, where a family member has an LTC.

### 1.1 | Background

The UK Department of Health (Department of Health, 2012) defines an LTC as: '*a condition that cannot, at present, be cured but is controlled by medication and/or other treatment/therapies*' (page 3). This definition is useful but does not capture the diversity in disease progression and the differences in impact on individuals and their families. Moreover, in the rest of the world, terminologies such as: 'chronic disease'; 'chronic illness'; 'chronic conditions'; 'disabling conditions'; 'long-standing disease'; and 'long-term conditions' are used interchangeably to describe illnesses of an enduring nature that have an impact on the individual's physical, mental and psychosocial well-being and have evolved as ways of thinking about the relationship between health and illness change (Bernell & Howard, 2016; Goodman, Posner, Huang, Parekh, & Koh, 2013; van der Lee, Mookink, Grootenhuis, Offringa, & Heymans, 2007). However, in the UK, the preference for using the term 'long term' as opposed to 'chronic' circumvents negative associations with the latter, which implies an unremitting and remorseless condition and may not represent lay perspectives. For the purposes of this review, the term 'long-term condition' will be used to refer to physical and/or mental health conditions that are permanent, necessitating ongoing health, social and, in the case of children educational support, for the individual and their family. We excluded cancers because of continuing debate throughout the period covered by our search, on the usefulness of classifying cancer as an LTC (Tritter & Calnan, 2002).

Typically, family members shoulder the greatest responsibility for care delivery and coordination, which can have an impact on their own health (Stacey, Gill, Price, & Taylor, 2018; Vaingankar, Subramaniam, Abdin, He, & Chong, 2012). Consequently, one individual's LTC can have an impact on the whole family (Golics, Basra,

Salek, & Finlay, 2013; Grey, Knafel, & McCorkle, 2006; Knowles et al., 2016; Roth et al., 2009; Ryan & Sawin, 2009). Findings from studies investigating the impact of living with an LTC are equivocal with both poor adaptation to living with their condition and psychosocial problems such as isolation, loss of identity, low self-worth and anxiety being reported (Bishop, Stenhoff, & Shepard, 2007; Kvaal, Halding, & Kvigne, 2014; Manning, Hemingway, & Redsell, 2013) and good adaptation reported in other studies (Cooper, Collier, James, & Hawkey, 2010; Martz & Livneh, 2016; Sanderson, Morris, Calnan, Richards, & Hewlett, 2010; Vaingankar et al., 2012). Similarly, findings from studies investigating the impact on family members living with an individual with an LTC are also equivocal, with both positive and poor adjustment reported (Golics et al., 2013; Roddis et al., 2016; Roth et al., 2009). The role of family members is significant in terms of their involvement in treatments and shaping illness perceptions (Årestedt et al., 2015; Hale, Treharne, & Kitas, 2007; Knowles et al., 2016; Ryan & Sawin, 2009).

Family involvement can help empower people to self-manage their condition (Shahriari, Ahmadi, Babaei, Mehrabi, & Sadeghi, 2013) and improve adherence to treatment regimens (Coleman, Roman, Hall, & Min, 2015; Jonkman et al., 2016). This in turn can reduce readmission rates (Coleman et al., 2015; Jonkman et al., 2016) and improve the individual's quality of life (QoL) (Hawton et al., 2011; Prazeres & Santiagol, 2016; Salyer, Schubert, & Chiaranai, 2012). Research also suggests that family support is associated with improved mental and physical health and reduces social isolation (Hawton et al., 2011; Prazeres & Santiagol, 2016; Salyer et al., 2012). A cross-sectional household survey of over 2,400 adults found that the supportive role of family and friends is a predictor of an individual's perceived illness burden (Vaingankar et al., 2012). Supporting individuals with an LTC and their families will require professionals to reconceptualize the traditional view of the family and the role of caregivers such as friends and neighbours. The traditional Western and legal, definition of *the family* as two or more persons related by birth, marriage, or adoption who reside together in a household, has less relevance in contemporary society, where families are increasingly diverse (Eshleman & Bulcroft, 2010). A broader, more comprehensive and accurate portrayal of human relationships defines the family as any social group where the members are concerned about and care for each other and are very interdependent and committed to each other (Eshleman & Bulcroft, 2010). People supporting individuals with an LTC could encompass a wide range of family members and close friends (Justo, Soares, & Calil, 2007).

Research has highlighted that professionals tend to adopt a reactive rather than proactive approach to supporting family caregivers (Knowles et al., 2016) and the UK Chief Medical Officer urged professionals to 'think family... at every interaction' to ensure family health and well-being are central to multi-professional practice and to develop innovative tools to support and promote family well-being (Department of Health, 2013:9). International evidence, particularly from North America, has found that family-focused care (FFC) is better than patient-centred care in improving the health and functioning of individuals with LTCs (Gillis, Pan, & Davis, 2019). However,

in the UK, family-focused care across the life course is not necessarily central to the delivery of health and social care. There is, therefore, an urgent need to evaluate interventions at individual, family and community levels that could support individuals, including those in the UK with an LTC, to reduce premature deaths of people from one or more LTCs (Daar et al., 2007; Goodwin, Curry, Naylor, Ross, & Duldig, 2010). Service level interventions include case managers working across health and social care services, individuals' self-management interventions such as health coaching (Goodwin et al., 2010) and, at a family level, psychosocial support and educational interventions (Yesufu-Udechuku et al., 2015).

There is a growing evidence base on FFC, with several published reviews available; studies typically focus on specific groups such as children (Foster, Whitehead, & Maybee, 2016a; Shield et al., 2012; Watts et al., 2014; Watts et al., 2014), older people (Kim & Park, 2017) or specific areas of services, for example, mental health services (Foster, Maybery, et al., 2016). Two published 'review of reviews', relating to family involvement in adult chronic disease need updating, Chesla (2010) included reviews from 2004–2009 and Gillis et al. (2019) from 2007–2016. While findings from these reviews highlighted that family-focused interventions have the potential to improve health outcomes for individuals with LTCs and their families, they did not consider: (a) how family life, family health and social care intersect, and (b) what psychologically, socially or behaviourally orientated tools/interventions exist to support and promote family-focused care for those with LTCs across the life course.

Following a brief scope of the literature and recognizing challenges in defining concepts associated with family care (Al-Motlaq et al., 2018; Reupert et al., 2018), we used the following working definition of FFC:

*Family-focused care is an approach to care delivery whereby health and social care professionals respect and respond to the needs of the individual and their family as a complete unit, recognizing the family role in supporting the individual with an LTC. For the purpose of this review, FFC incorporated the terms 'family-centred care', 'family-centred practice' and 'family-focused practice'.*

## 2 | THE REVIEW

### 2.1 | Aim

The aim of this study was to summarize the findings of systematic reviews of FFC interventions in supporting families across the life course and answer the following questions:

1. How is FFC defined?
2. In what health and social care disciplines, contexts, settings and countries have studies of FFC been undertaken?
3. What FFC interventions are used to support families where a family member has a long-term condition?
4. How have FFC interventions been evaluated in relation to their clinical and cost-effectiveness?

## 2.2 | Design

Umbrella reviews compile evidence from multiple research syntheses to summarize existing evidence but do not re-synthesize existing synthesized data (Aromataris et al., 2017). This design was chosen because: (a) As the number of single studies focusing on family interventions, particularly in nursing, grows so does the number of published synthesis reviews; (b) Notwithstanding the challenges of undertaking an umbrella review across different cultures, countries and contexts, there have been limited attempts to consider family-focussed interventions across both health and social care and across the lifespan; and (c) An umbrella review afforded a means for reporting on the current direction and future priorities of family-focused interventions across health and social care.

We followed the Joanna Briggs Institute (JBI) (Aromataris et al., 2017) methodology of umbrella reviews guidance. All authors were members of the review team. In addition, the review benefitted from the input of seven service users and carers, with a range of experiences across health and social care settings, who contributed to the review protocol development and review team meetings. The review was registered on PROSPERO (the prospective register of systematic reviews international database) (registration number: CRD42017075858).

## 2.3 | Search methods

Reviews were included if they met the following selection criteria:

- Evaluated FFC or related concepts (family-centred care; family-centred practice; family-focused practice) in relation to interventions (e.g. family therapy, psychotherapy, peer to peer support, counselling, education) that aimed to support FFC or the related concepts described above.

Reviews spanning the life course and all care contexts (acute, primary and community health and social care) were included.

Reviews were excluded if they were:

- Not published in the English language.

The types of review included are presented in Table 1.

Population	Long-term health condition; long-term physical health condition; long-term mental health conditions; chronic illness, specific physical condition (asthma, diabetes, stroke, heart disease, chronic obstructive airway, epilepsy diseases) or specific mental health conditions (depression, dementia)
Phenomena of interest	Family-focussed care, family-centred care, family-centred practice or family-focused practice
Review design	Systematic reviews; meta-analyses; meta-ethnographies; meta-syntheses; meta-reviews; mixed method reviews; realist reviews; integrative reviews; narrative reviews

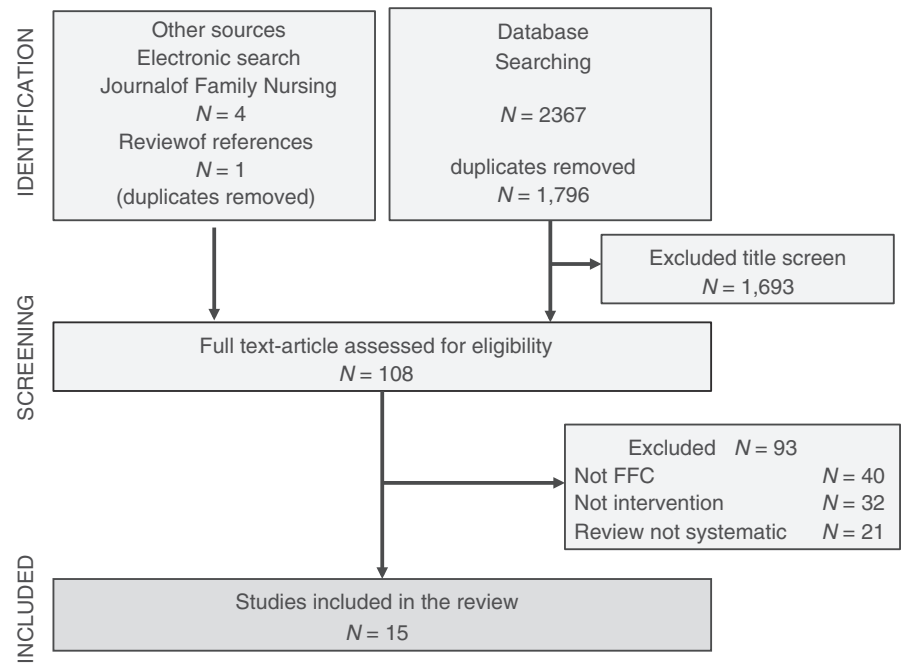
The PiCo (Population, Phenomena of Interest, Context) framework guided the search terms. Population reflected individuals across the life course and included both adults and children with LTCs. In addition, a range of specific conditions was searched for; conditions were identified by reviewing data on the most prevalent LTCs (Department of Health, 2012) and working with our service user and carer group to identify conditions across the life course and included both physical and mental health conditions. Contexts reflected health and social care settings. We did not apply date restrictions. The final search was undertaken in February 2019. The search (Table S1) was developed from the concepts presented in Table 1.

A range of health and social care databases were searched: Medline (1946–2019) (Ovid); Medline R and Epub Ahead of Print (Ovid) (2015–2019); Cochrane Database of Systematic Reviews (Wiley) (2019); Database of Abstracts of Reviews of Effect (Wiley) (2019); EMBASE Classic and EMBASE (Ovid) (1947–2019), CINAHL (EBSCO) (1981–2019), Health Technology Assessment Database (Wiley) (2019); PsycInfo (Ovid) (1806–2019), In-Process & Other Non-Indexed Citations (Ovid) (2015–2019). The development of the search strategy was supported and undertaken by an information scientist and was peer reviewed by a second senior information scientist. References of two published 'review of reviews' relating to family involvement in adult chronic disease (Chesla, 2010; Gillis et al., 2019) and electronic copies of the Journal of Family Nursing were searched for relevant published articles for a 10-year period up to February 2019 because of the journals relevance to the focus of our review. These led to five additional systematic reviews being identified (Figure 1).

## 2.4 | Search outcome

After duplicates were removed, the search returned 1,796 potential articles (Figure 1); all authors screened titles and abstracts by working in groups of two or three, each group being allocated a different cluster of papers. Titles and abstracts were independently reviewed before reaching a consensus on which of the selected articles initially met the selection criteria for full review. A screening template was used to ensure consistency across groups, which was piloted with all reviewers reviewing the same four articles to ensure we were consistent in applying our selection criteria. Full article screening of 108 articles involved working in groups of two or three again, with each group reviewing 36 articles (Figure 1).

**TABLE 1** Search concepts

**FIGURE 1** PRISMA flow chart of search

Each allocated article was independently read in-depth before reaching group consensus as to which articles met the inclusion criteria. Independent reviewing and consensus agreement is essential to reduce bias in an umbrella review (Aromataris et al., 2017). The process resulted in 15 reviews being included, reporting a total of 290 original studies (after removal of duplicates), across 309 publications (Table S1).

## 2.5 | Quality appraisal

The validated AMSTAR measurement tool was used to assess methodological quality of included reviews (Shea et al., 2007). The 11 AMSTAR questions focus on assessing the methodological rigour of each review recording 'yes' if criteria are met and 'no' if the criteria are not met or not stated (Table S2).

## 2.6 | Data abstraction

We adapted the JBI exemplar data extraction template to meet the review objectives. After piloting, the template was modified slightly to enable the terms associated with FFC and the review design to be recorded. To minimize bias, all authors contributed to data extraction with JS independently reviewing all included reviews as an additional quality check.

## 2.7 | Synthesis

We did not undertake a statistical pooling of the findings because (a) Umbrella reviews do not re-synthesize existing synthesized

data and (b) heterogeneity of the included reviews. We summarized key characteristics from each review such as phenomena of interest, population/ context, intervention and outcomes measured (Table 2; Table S3). We used the information in Table 2 and Table S3 to map the findings from the reviews in relation to our review questions (Table S4), which formed the basis of the narrative presented below.

## 3 | RESULTS

Fifteen reviews, reporting a total of 290 original studies, met the inclusion criteria. Five reviews were excluded at data extraction stage, one because of only tenuous links to FFC (Woods, Spector, Jones, Orrell, & Davies, 2005) or interventions (Berge & Patterson, 2014), one aimed to develop a framework for family management of LTCs rather than evaluate interventions (Knafl, Deatrick, & Havill, 2012) and two that, although initially judged relevant, focused on children in hospital and were not specific to children with LTCs (Foster, Whitehead, et al., 2016; Foster, Whitehead, Maybee, & Cullens, 2013). The included reviews are summarized in Table 2, with additional detail provided in Table S3.

### 3.1 | Characteristics of included reviews

The reviews encompassed a range of LTCs, patient groups, settings and interventions and differed in terms of design (Table 2). The review designs were systematic quantitative reviews (Canter, Christofferson, Scialla, & Kazak, 2019; Deek et al., 2016; Harper et al., 2015; Kuhlthau et al., 2011; McBroom & Enriquez, 2009; Torenholt, Schwennesen, & Willaing, 2014), Cochrane systematic

TABLE 2 Summary of methods, characteristics and key findings of reviews (N = 15)

Author (year)	Review typology	Number of studies (publications)	Phenomena of interest	Population/context	Interventions	Primary outcomes measured
Canter et al. (2019)	Systematic review	22 (23)	Family-focused care	Children with chronic illness	eHealth interventions	1. Impact on family systems outcome behaviours 2. Family process 3. Family relationships
Deek et al. (2016)	Quantitative systematic review	10	Family-focused care	Family carer living with a person with a long-term condition	Education interventions focused on self-care strategies and coping skills	1. QoL 2. Readmission rates 3. Improved self-care 4. Medication adherence
Elvish et al. (2013)	Systematic review – mixed methods	20	Family care giving	Carers of people with dementia	Caregiver interventions such as skill building, education and support	1. Broad goals such as improved subjective psychological well-being of carers 2. QoL 3. Effect of caring burden and depression
Harper et al. (2015)	Systematic literature review	13 (14)	Patient and family-centred	Children with asthma	Programmes that support family to plan, delivery, manage care	1. Non-specific clinical care outcomes such as symptom reduction, symptom-free days, acute asthma episode
Hartmann et al. (2010)	Review and meta-analysis	52 (65)	Family-oriented care	Cardiovascular diseases including stroke, and cancer and arthritis	Psychological educational interventions – relationship focused	1. Physical and mental health Family members' health.
Justo et al. (2007)	Cochrane systematic review	7	Family-focused care	Individuals with bipolar disorders	Family psychological interventions such as therapy or education	Primary outcomes were 1. Change in illness status and relapse rates, anxiety, depression 2. Relapse rates
Kuhlthau et al. (2011)	Systematic review	24	Family centred-care	Children with disabilities and other LTCs (conditions) and their families	Interventions unclear but included any 'activity' that promoted FCC	1. Health, mental health & well-being 2. Satisfaction with care 3. Efficient use of healthcare resources 4. Access & communication 5. Family functioning/impact on families 6. Improved transition to adulthood 7. Improvements to provider systems
Martire et al. (2010)	Review and meta-analysis	33 (40)	Family-focused care	Couples or dyads one person with chronic illness including cancer, arthritis, CVD, chronic pain, HIV, T2D HIV, Type 2 diabetes	Psychosocial or behavioural interventions	1. Psychological function (e.g. depressive symptoms, coping, self-efficacy, anxiety) 2. Physical health indicators (e.g. biomedical markers, pain) 3. Marital functioning

(Continues)



TABLE 2 (Continued)

Author (year)	Review typology	Number of studies (publications)	Phenomena of interest	Population/context	Interventions	Primary outcomes measured
Martire (2005)	Review and meta-analysis	12 (14)	Family-focused care	Heart disease, arthritis, chronic pain, and Type 2 diabetes	Psychosocial interventions such as cognitive-behavioural therapy or skills training, education and support	<ol style="list-style-type: none"> <li>1. Patient and family: family functioning, self-efficacy, pain, disability, coping, marital adjustment</li> <li>2. Psychological function (e.g. depressive symptoms, coping, self-efficacy, anxiety)</li> <li>3. Physical health indicators</li> </ol>
Martire et al. (2004)	Review and meta-analysis	70 (72)	Family-focused care	Dementia, heart disease, frail older adults, cancer, chronic pain, stroke, rheumatoid arthritis, traumatic brain injury	Non-medical interventions that are psychologically, socially or behaviourally oriented	<ol style="list-style-type: none"> <li>1. Patient outcomes (depression, anxiety, relationship satisfaction, disability and mortality)</li> <li>2. Family member outcomes (depression, anxiety, relationship satisfaction and caregiving burden)</li> </ol>
McBroome and Enriquez (2009)	Systematic review	9	Family-centred care	Children aged between 8–17 diagnosed with Type 1 diabetes	Family-focused intervention that supports family manage care	<ol style="list-style-type: none"> <li>1. Improving diabetes clinical indicators such as blood profiles</li> <li>2. Improving family relationships/decreasing conflict</li> </ol>
Östlund and Persson (2014)	Integrative review	17	Family systems nursing	Patients and their families (spouses and/or children)	Interventions based on family systems nursing theory	<ol style="list-style-type: none"> <li>1. Cognitive, affective and behavioural domains of family functioning</li> </ol>
Torenholt, Schwennesen, and Willaig (2014)	Systematic review	10	Family-based/centred approaches to care	Adults with Type 1 and Type 2 diabetes	Education or support interventions	<ol style="list-style-type: none"> <li>1. Biological with HbA1c frequently used outcome measure calorie and exercise goals</li> <li>2. Psychosocial outcome measures</li> <li>3. Family-specific outcome measures relating to involvement, support and functioning</li> </ol>
Urban et al., 2004	Unclear appears to be a narrative synthesis	29 (33)	Family-focused care	Adolescents with Type 1 diabetes	Interventions aimed at maintaining parent-adolescent teamwork in diabetes management tasks	<ol style="list-style-type: none"> <li>1. Parent involvement in insulin administration:</li> <li>2. Intra-family conflict;</li> <li>3. Metabolic control (HbA1c levels); frequency of blood glucose monitoring and insulin dosages</li> <li>4. Metabolic control such as hypoglycaemic events</li> <li>5. Accessing health professionals</li> </ol>
Van Horn et al. (2002)	Integrative literature review	13	Family-focused care	Adult cardiac patients	Education or support interventions for targeted spouses	<ol style="list-style-type: none"> <li>1. No clear outcomes assessed but included in feelings of hope or perceived social support, knowledge and confidence</li> </ol>



review (Justo et al., 2007), meta-analyses (Hartmann, Bazner, Wild, Eisler, & Herzog, 2010; Martire, 2005; Martire, Lustig, Schulz, Miller, & Helgeson, 2004; Martire, Schulz, Helgeson, Small, & Saghafi, 2010), a mixed method review (Elvish, Lever, Johnstone, Cawley, & Keady, 2013), integrative reviews (Östlund & Persson, 2014; Van Horn, Fleury, & Moore, 2002) and a narrative synthesis (Urban, Beery, & Grey, 2004). The range of review designs is expanding (Grant & Booth, 2009); an important aspect of the review reported here is that the included reviews followed explicit and reproducible methods to identify, evaluate and summarize the findings of included studies.

The reviews differed in terms of research methods reported; most were primarily reviews of quantitative studies (Kuhlthau et al., 2011; Torenholt et al., 2014; Urban et al., 2004; Van Horn et al., 2002), predominantly randomized controlled trials (Canter et al., 2019; Deek et al., 2016; Harper et al., 2015; Hartmann et al., 2010; Justo et al., 2007; Martire, 2005; Martire et al., 2004, 2010; McBroom & Enriquez, 2009), with two reviews including both quantitative and qualitative designs (Elvish et al., 2013; Östlund & Persson, 2014). The number of studies included ranged from 7 (Justo et al., 2007) to 70 (Martire et al., 2004); reviews with a smaller number of included studies typically focused on one specific condition (Table 2).

### 3.2 | Quality evaluation of the reviews

The quality of the selected reviews was variable (S2). The only criterion all reviews met was undertaking a comprehensive search (Item 3). Providing a list of both included and excluded studies (Item 5), quality appraisal (Item 7), reporting bias (Item 10) and reporting conflicts of interest (Item 11) were poorly described.

### 3.3 | Defining FFC

There was little evidence to suggest definitions of FFC were used to guide the reviews with the exception of Harper et al. (2015) (Table S3). Four reviews did, however, describe components of FFC, specifically in relation to family-centred care (Canter et al., 2019;

Deek et al., 2016; Kuhlthau et al., 2011; Östlund & Persson, 2014). Active ingredients of FFC included implementing interventions that improve family outcomes and establishing positive relationships and effective partnerships between professionals and families.

### 3.4 | Study contexts

All reviews were undertaken in healthcare environments, with both in-patient and community settings represented (Table S3). Inclusion criteria ranged from specific LTC conditions such as asthma (Elvish et al., 2013) and cardiac diseases (Hartmann et al., 2010; Van Horn et al., 2002), a group of conditions such as bipolar disorders (Justo et al., 2007) and others representing a broad range of LTCs (Deek et al., 2016; Kuhlthau et al., 2011; Martire, 2005; Martire et al., 2004, 2010; Östlund & Persson, 2014). Three reviews focussed specifically on the relationship between FFC interventions, clinical outcomes and family outcomes such as family functioning or relationships for individual with diabetes (McBroom & Enriquez, 2009; Torenholt et al., 2014; Urban et al., 2004). The countries where component studies were undertaken are presented in Table 3. Most research relating to FFC appears to originate in the USA, although it is noteworthy that two of the reviews, representing 37 original studies, only included studies from the USA as part of their selection criteria (Harper et al., 2015; Kuhlthau et al., 2011).

### 3.5 | Evaluation of FFC interventions in relation to their clinical and cost-effectiveness

While it was difficult to ascertain whether the interventions evaluated were specifically aimed at promoting FFC, they all appeared to have a family component. Many of the interventions were either educational or psycho-educational (Deek et al., 2016; Elvish et al., 2013; Harper et al., 2015; Hartmann et al., 2010; Justo et al., 2007; Martire, 2005; Martire et al., 2004, 2010; Torenholt et al., 2014). Similarly, a range of outcome measures were used to evaluate the effectiveness of interventions, for example: Quality of Life (QoL) measures (Deek et al., 2016; Elvish et al., 2013; Hartmann et al., 2010;

North America	Europe	Australasia	Other
USA	226	UK	45
Canada	207	Sweden	18
	19	Netherlands	10
		Denmark	5
		Iceland	3
		Norway Finland	2
		Italy	1
		Ireland	1
		Switzerland	1
		Germany	1
		Spain	1
			1
			1
		Australia	8
		New Zealand	6
			2
		Taiwan	11
		Brasil	3
		Chile	1
		China	1
		Iran	1
		India	1
		Mexico	1
		Thailand	1
		Multisite: USA/UK/	1
		Australia	1

TABLE 3 Geographical locations of studies included in the reviews (N = 290)

Justo et al., 2007; Van Horn et al., 2002); disease-specific clinical/biological health measures (Justo et al., 2007; Martire et al., 2010; McBroom & Enriquez, 2009; Torenholt et al., 2014); mental health status such as depression and anxiety measures (Elvish et al., 2013; Justo et al., 2007; Martire et al., 2010); self-care measures such as treatment adherence (Deek et al., 2016; Justo et al., 2007); service-related measures such as hospital readmission rates (Deek et al., 2016; Justo et al., 2007; Martire et al., 2010; McBroom & Enriquez, 2009; Torenholt et al., 2014; Urban et al., 2004) and outcomes relating to family functioning/family relationships (Canter et al., 2019; Kuhlthau et al., 2011; Martire et al., 2010; Martire, 2005; McBroom & Enriquez, 2009; Östlund & Persson, 2014; Torenholt et al., 2014).

One review attempted to assess clinical and cost-effectiveness of interventions and found that interventions which reduce hospital admission rates could have a potential cost-saving effect (Harper et al., 2015). Overall, there was limited evidence to suggest that FFC interventions have a statistically significant impact on clinical outcomes for either the individual or the family. However, while lacking statistical significance, some tentative links were made between FFC interventions and improved QoL and/or psychosocial well-being for both the individual with an LTC and family members (Elvish et al., 2013), improved self-care and greater empowerment of the individual to manage their condition (Deek et al., 2016) and improved satisfaction with care (Harper et al., 2015; Kuhlthau et al., 2011). Two reviews suggested multicomponent interventions that address a range of individual and family needs such as skill development and psychosocial support may be more effective than a single component intervention (Elvish et al., 2013; Martire et al., 2010). Evaluating the economic benefits of interventions remains challenging.

## 4 | DISCUSSION

The purpose of this review was to investigate evidence for the clinical and cost-effectiveness of interventions, conforming to our applied definition, of FFC. Overall, the evidence was equivocal for the clinical and cost-effectiveness of FFC interventions for individual and family outcomes. However, there are indications that FFC may be more likely to be achieved using complex interventions (Elvish et al., 2013; Martire et al., 2010). Multicomponent interventions will be necessary to support families, across the life course, where a family member has an LTC. These would need to be delivered by a range of professionals across health and social care contexts (Petticrew, 2011). The reporting of complex interventions such as FFC has been criticized for not always including all 'ingredients' of the intervention (Harris, Croot, Thompson, & Springett, 2015). Furthermore, the UK Medical Research Council guidelines on complex interventions development emphasize that interventions must be theory driven (Craig et al., 2008) to understand how interventions work and to achieve the best outcomes (De Silva et al., 2014). A poorly conceptualized phenomenon results in interventions that are rarely well developed (De Silva et al., 2014). There appears to be a lack of conceptual clarity in relation to FFC, and therefore, we applied an

a priori definition to guide this umbrella review that enabled us to begin to engage with the heterogeneity of the concept of FFC. We found little evidence of theory being used to guide FFC research (Deek et al., 2016; Kuhlthau et al., 2011) and a lack of theoretical or conceptual underpinning of intervention development (Martire et al., 2010; Torenholt et al., 2014). Models such as 'the family management style framework' describing how families respond to incorporating the needs of a child with an LTC within family life (Knafl et al., 2012) could be used by family researchers to frame their research when evaluating family-focused interventions across the life course.

Without a clear definition of FFC or explicit theoretical foundations to underpin FFC, it will remain challenging to understand the relationship between FFC interventions and their usefulness in supporting individuals with an LTC and their families (Berge & Patterson, 2014). Defining and understanding the core attributes of a concept, such as FCC, is essential to understand the relationship between variables (Walker & Avant, 2011), in this case whether interventions benefit the individual with an LTC and their family (Gillis et al., 2019). Lack of clarity about the concept being investigated, as in this umbrella review, added to the challenges of comparing studies and assessing the effectiveness of interventions in terms of individual and family outcomes and their relevance to health and social care practice. Failure to agree a definition of FFC leaves us without appropriate frameworks to develop interventions to guide practice and makes it challenging to embed into practice (Knafl, 2015). This could be addressed in future work by undertaking a concept analysis and/or research to ascertain the key components of FFC.

Despite attempts by policy makers and professional organizations to promote FFC across the life course and interagency collaboration and although 15 reviews, reporting a total of 290 original studies were identified in this umbrella review, evidence that FFC interventions have an impact on clinical outcomes for either the individual or the family is still not clear and further investigation is required. However, non-significant results do not always demonstrate that the intervention is ineffective, especially when the methodological quality of these studies is questionable. We identified a lack of research relating to FFC, particularly across health and social care settings, to support its implementation or evaluation. Our review suggests that most relevant research originates in the USA (Table 3) and while recognizing the value of findings from international perspectives, embedding FFC into practice should consider different contexts. In relation to family-centred care, research suggests that health professional perceptions of family-centred care varied between countries, which may reflect different care priorities and service delivery systems (Feeg, Paraszczuk, Cavusogulu, Shileds, & Al Mamum, 2015). Consideration should be given to the interface between health and social care services and whether working within a framework of FFC could ensure that the needs of both the individual with LTCs and their families are met. Indeed including families as a formal mechanism within care may facilitate integration more effectively.

Heterogeneity across reviews was considerable: a wide range of FFC interventions were evaluated using a range of outcome measures. However, reviews appeared to focus on three areas of FFC (Table S3): (a) identifying interventions that can improve clinical outcomes, for individuals with LTCs and families; (b) identifying interventions that can improve QoL and overall well-being for individuals with LTCs and family members; and (c) improving family systems and family relationships. Therapy-based interventions have the potential to improve QoL and/or psychosocial well-being for both the individual with an LTC and family members (Elvish et al., 2013; Hartmann et al., 2010; Justo. et al., 2007). In addition, FFC interventions that aim to improve self-management and family contributions to care by developing the skills required to manage the LTC can foster independence in monitoring symptoms, optimizing medicine adherence and improve problem-solving (Jonkman et al., 2016). While intervention studies can determine the effectiveness of FFC, there is an additional evidence gap in relation to translating knowledge into practice (Östergaard & Wagner, 2014). The role of health and social care professionals in supporting both the individual with LTC and their family could include assessment and appropriate interventions that meet the needs of individuals with an LTC and their families.

Improving individual and family outcomes, across the life course can often be best achieved by the integration of health and social care teams (Thistlethwaite, 2011). Effective inter-disciplinary and inter-agency collaboration is relevant for people with LTCs, where the interplay between health and social care needs is recognized and particularly for individuals with multiple conditions. As the role of the family gains prominence in supporting individuals with LTCs, interventions and new models or frameworks are required to ensure the future needs of individuals with an LTC are met and families are supported (Grey et al., 2006). In addition to developing a shared understanding of FFC across health and social care, consideration should be given to whether and how health and social care professionals meet individual's and families' needs within a framework of FFC, particularly if family dynamics result in conflicts in relation to managing an individual's LTC. Researchers need to develop and test interventions that benefit individuals with LTCs and their families to ensure outcomes are maximized across the life course (Östergaard & Wagner, 2014). On a cautionary note, developing interventions aimed at promoting FFC could result in intervention-generated inequality; those without family or with challenging family dynamics may struggle to access care.

Our review has confirmed a lack of research relating to FFC interventions that support individuals with LTCs and their families. Therefore, there is a need for a conceptual analysis relating to FFC to develop a coherent conceptually grounded framework that is essential to drive practice and evaluation. In addition, a qualitative review of FFC or related concepts may help understanding by reporting specifically on how individuals with LTCs and health and social care professionals perceive and experience FFC.

The main strength of this umbrella review was the systematic way the JBI guidelines were followed, with clearly reproducible

methods adopted to identify and describe the findings of the included studies. The process for identifying reviews including quality assessment and data extraction was undertaken by a process of peer consensus at each stage to reduce biases, with each stage of the review methods piloted to ensure consistency.

Like all reviews, there are limitations; the concept of FFC is poorly defined and we may not have identified relevant studies that used different terms to those we included. While we searched a range of databases, this may not have been exhaustive and we only included studies published in the English language. Included reviews were predominately reviews of RCTs that in general reported findings that were not statistically significant. Only two reviews considered publication bias (Deek et al., 2016; Hartmann et al., 2010) with the latter undertaking a sensitivity analysis to determine if the pooled effect size was dependant on the quality of the study and did not find any significant results.

## 5 | CONCLUSION

As the number of people living with one or more LTC increases, ensuring FFC interventions are effective in supporting both the individual and their family in managing the LTCs will remain a key priority across the life course. This umbrella review reports findings from 15 systematic reviews, to establish what FFC interventions have been evaluated and if they are clinically and cost-effective. We found the evidence inconclusive. Without a clear definition of FFC, there will remain challenges in developing and testing interventions and embedding the concept in practice. There is a need to better understand the extent to which FFC interventions could improve the health and well-being of individuals with LTCs and their families.

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## CONFLICT OF INTEREST

The authors declare no conflict of interest in relation to undertaking the review, authorship and publication of this article.

## AUTHOR CONTRIBUTIONS

Joanna Smith co-ordinated the review process and development of the review protocol; led the development of the article, title, abstract and full article screening; quality appraisal; data extraction analysis and synthesis. David Saltiel, Hannah Fairbrother, Jill Thompson, Parveen Ali, Penny Curtis, Susan Kirk, Veronica Swallow and Yvonne Birks contributed to the development of the review protocol, contributed to developing the article, title, abstract and full article screening, quality appraisal, data extraction analysis and synthesis.

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Additional supporting information may be found online in the Supporting Information section.

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