

Original Article

## Ethical Issues Associated with Family Involvement in Patient Care: A Scoping Review

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### Abstract

**Background:** Family caregivers play an important role supporting patients across the care continuum. However, caregivers and health care professionals can experience ethical concerns related to family involvement in patient care. Ethical concerns can include aspects of privacy in relation to patient health information, respect for autonomy and conflicting moral choices. To date, there has not been a synthesis of the literature examining ethical concerns related to caregivers' involvement in patient care.

**Objective/Aims:** This study explores and synthesizes the extent, range, and nature of ethical concerns regarding family involvement in adult patient care.

**Methodology:** A scoping review guided by Arksey and O'Malley was undertaken. A search was conducted on EMBASE, EBP Database, Medline, Web of Science, PsycINFO, and CINAHL. Articles that were written in English, peer-reviewed, and discussed ethical concerns involving families in adult or older adult patient care were included. Data was extracted using a data extraction form and analyzed through conventional content analysis.

**Results:** The review included 57 articles and included five primary ethical concerns. Synthesis of these ethical concerns resulted in six themes: communication between healthcare professionals, and caregivers; end-of-life decision making; truth within boundaries related to the provision of care; privacy considerations

in the electronic tracking of people; discrepancies between caregiver and patient care preferences; and caregivers' decisions to be involved in patient care. Characteristics of these themes varied by illness population.

**Conclusions:** Future research and clinical initiatives to develop and implement models of care that support family involvement in patient care must address these context specific ethical considerations.

**Keywords:** families, caregivers, scoping review, ethics

## Introduction

Family-centered care (FCC) is being widely incorporated in health care settings. FCC is involvement of the patient, their family, and health care professionals (HCPs) in planning, delivering, and evaluating health care services (Kokorelias et al., 2019).

In the context of FCC and current privacy legislation, including family caregivers in a patient's circle of care can create opportunities for ethical concerns to emerge (e.g., issues of privacy, informed consent) (Kapp, 1992). Studies have identified multiple ethical concerns including: maintaining patient confidentiality (Chan and O'Brien, 2011), respecting patients' autonomy (Kelly et al., 2012), adhering to patients' privacy boundaries (Landau et al., 2010), moral choices (Murphy, 2008), and dual-role tensions of family members being both caregivers and sources of information (Chen, 2008). To date, this literature has not been synthesized to enhance our understanding of the scope of ethical issues and their impact on care provision. A synthesis will provide a starting point for HCPs and researchers in diverse care settings (e.g., community, acute care, rehabilitation) to become more aware of ethical concerns that may impact FCC. Therefore, the purpose of this scoping review was to understand the extent, range, and nature of ethical concerns regarding family involvement in adult patient care.

## Methods

A scoping review was undertaken, as this is considered useful when a topic has not previously been comprehensively reviewed (Arksey and O'Malley, 2005, Colquhoun et al., 2014). The methodological framework suggested by Arksey and O'Malley (2005) guided the study. The manuscript adheres to

The Preferred Reporting Items for Systematic Reviews and Meta-Analysis - Extension for Scoping Reviews (PRISMA-ScR) criteria (Tricco et al., 2018) (**Appendix A**). A protocol was not registered prior.

### (1) Identifying the Research Question

The research question was: "What ethical concerns are associated with family involvement in adult and older adult patient care?"

### (2) Identifying Relevant Studies

We sought to identify available literature reporting on ethical concerns in family involvement in adult care published in English prior to July 30 2022. Studies were identified using Ovid's EMBASE, EBP database, Medline, PsycINFO, CINAHL on the Ebsco platform, and Web of Science (see **Appendix B** for a sample of the search strategy). We searched for literature published between 1980 - July 30, 2022, as research with family caregivers emerged in the early 1980s. All search results were uploaded onto Covidence (cite?). Duplicates were removed and a total of 1070 articles were screened. A hand search of the reference lists of included articles was conducted following the full-text review process, and this resulted in 17 additional articles.

### (3) Study selection

Title and abstract and full-text screening were completed in duplicate. Five authors ([Initials Blinded for Review]) independently conducted title scans and abstract reviews and full text reviews to assess eligibility against the following inclusion criteria: (1) English, peer-reviewed article; (2) discussed ethical

concerns involving family in adult patient care. Studies were excluded for the following reasons: no mention of ethical concerns in relation to family involvement in patient care, commentary/editorial, pediatric population, and articles not available. Gray literature was also excluded. Any conflicts were resolved through team-discussion and consensus with the senior author.

#### (4) Charting the Data

Following the recommendations by Levac et al. (2010), the research team discussed data characterization and extraction methods at the beginning, during the middle, and at the end of the review process. At the beginning of the review process, [Initials Blinded for Review] and [Initials Blinded for Review] developed a charting form that included information on study characteristics and findings related to ethical concerns and their descriptions. [Blinded for Review] and [Blinded for Review] discussed and extracted data from three articles together using a data extraction form. After this discussion, data extraction forms were refined, and reviewers independently extracted data from remaining articles. [Blinded for Review] and [Blinded for Review] reviewed all extracted data against the articles to ensure accuracy of the extracted data. Throughout the screening and data extraction process, the reviewers met bi-weekly to clarify uncertainties. Articles were not critically appraised.

#### (5) Data synthesis

Extracted data were analyzed using a qualitative content analysis (Saldaña, 2021). Following coding, the authors developed themes representing the ethical concerns present within the articles. Research team discussions helped to refine and finalize the themes. The number of articles discussing each theme was determined. The patient populations included in each category are also summarized.

## Results

Fifty-seven articles were included in this review (see **Figure 1**).

Various family members were included with the majority being partners, children, or parents. HCPs varied with the most common being social workers, physicians, and nurses. Studies included various patient populations with the most common including dementia, mental illness, and cancer (see **Table 2**). Not all studies reported sample size, age or the gender of participants, or patient population.

Five ethical concerns were identified: confidentiality/privacy (e.g., not sharing personal information), deception (e.g., providing false information), coercion (e.g., persuading someone to do something), withholding treatment and information, and patient and caregiver autonomy to make decisions. These concerns were summarized into six themes describing how these ethical concerns are presented in the context of family involvement in patient care (each described below): (1) communication between HCPs and caregivers; (2) end-of-life decision making; (3) truth within boundaries related to the provision of care; (4) privacy considerations in the electronic tracking of people; (5) discrepancies between caregiver and patient preferences; and (6) caregiver's degree of choice to be involved in patient care. These issues are visually represented in **Figure 2** where the ethical concerns provide the foundation from which these concerns interact in the context of caregiving (e.g., the themes). The ethical concerns related to the sharing of personal health information and patients' autonomy to make decisions cut across many of these themes.

**Communication between HCPs and caregivers:** Communication difficulties primarily occurred in 30 articles (53%). In the studies that reported patient populations, communication difficulties primarily occurred in the context of mental illnesses (e.g., schizophrenia, bipolar disorder). Confidentiality/privacy was the most common ethical concerns experienced by HCPs and

caregivers. HCPs often experienced challenges with deciding the amount of patient information to share with caregivers, and this in turn impacted how caregivers made decisions as family decision-makers for patients (Tracy et al., 2004, Marshall and Solomon, 2003, Madeo et al., 2008, Livingston et al., 2010, Aujoulat et al., 2002, Robert et al., 2020). Conversely, when HCPs shared patient information with caregivers, they were concerned about breaching patients' privacy (Pérez-Cárceles et al., 2005, Petronio and Sargent, 2011).

Caregivers similarly experienced challenges, such as obtaining patients' medical information from HCPs. When caregivers were unable to obtain relevant information, they felt excluded, undervalued, disempowered, neglected, and isolated (Cree et al., 2015, Gray et al., 2008, Doornbos, 2002, Lavoie-Tremblay et al., 2012, McNeil, 2013, Wainwright et al., 2015, Wilkinson and McAndrew, 2008, Wynaden and Orb, 2005). With limited information, caregivers found it difficult to follow through with care plans and this consequently affected the quality of care they were able to provide to patients (Dawson et al., 2017).

Caregivers also experienced challenges in determining when and how to share patient information with HCPs without jeopardizing the caregiver-patient relationship (Petronio et al., 2004). They feared HCPs may inform the patient of the information shared, resulting in an adverse effect on their relationship (Jankovic et al., 2011, Petronio et al., 2004). Ethical concerns arise from HCPs' attempts to balance patients' rights to confidentiality with caregivers' desire for communication, ultimately affecting how much patient information HCPs decide to disclose (Chen, 2008, Banks et al., 1986, Bute et al., 2015, Stanley et al., 2008).

**End-of-life decision-making:** Ten studies (17.5%) with various patient populations related to end-of-life decision making. The predominant ethical concerns related to privacy concerns limiting information shared with caregivers affecting their abilities to make confident decisions and autonomy to make these decisions in the context of families. At the

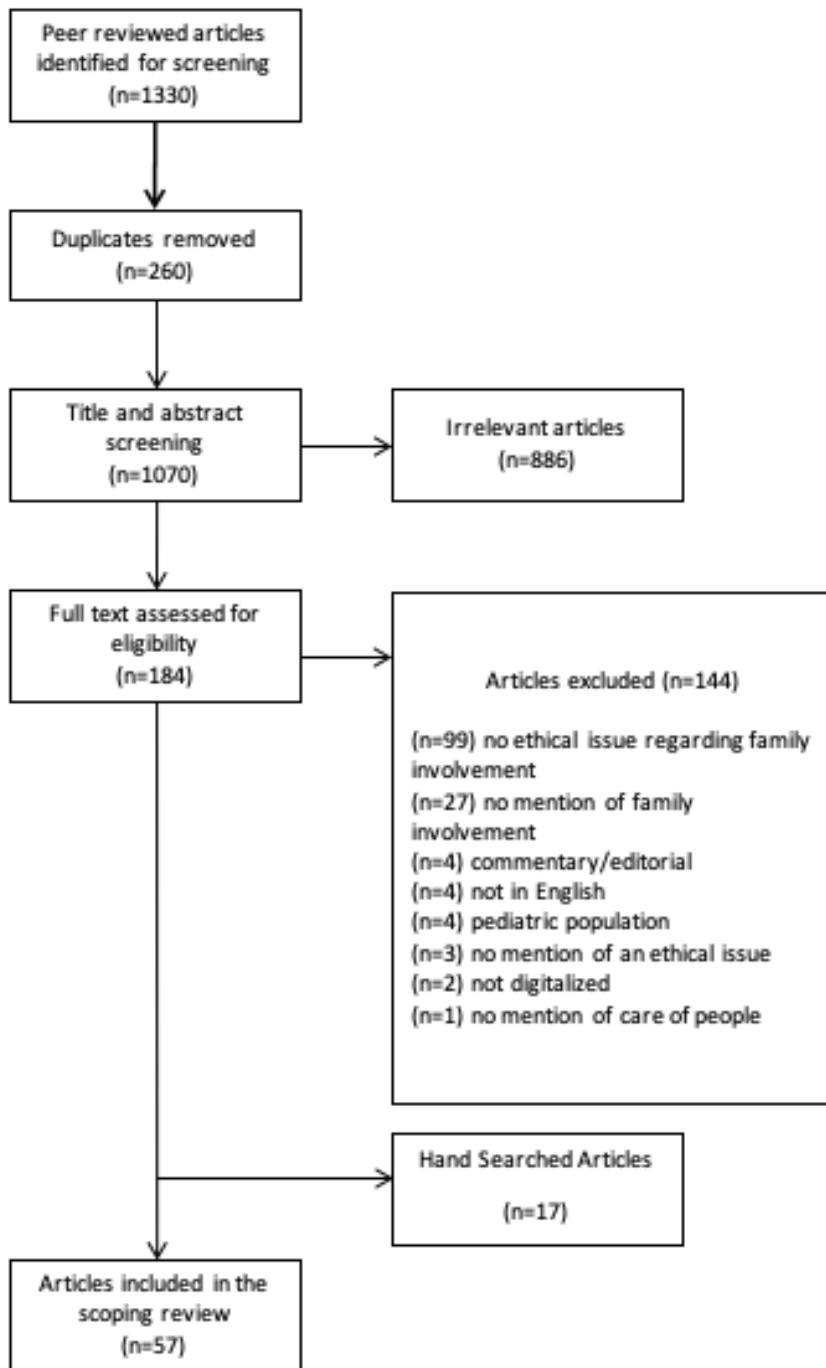
end-of-life, family caregivers became more involved in decision-making especially in circumstances where patients lacked cognitive capacity or were unable to participate in the decision-making process (Dreyer et al., 2009). Caregivers experienced difficulty in end-of-life decision-making due to uncertainty associated with patient care preferences and lack of advance care directives (Cho et al., 2020). In these instances, caregivers felt pressured and stressed when making end-of-life decisions on behalf of patients as they believed they were ill-equipped to make these important decisions (Petriwskyj et al., 2013). Caregivers expressed concerns about imposing their own beliefs when making these types of decisions (Cho et al., 2020). Caregivers also experienced conflict with other family members. In one case study, disagreements occurred between a caregiver and a patient's parents due to differing beliefs about medical treatment at the end-of-life (Roscoe et al., 2006). The caregiver's decision was questioned by family members despite the caregiver knowing the patient's desires and being designated by the patient to be the substitute decision-maker (Roscoe et al., 2006). Therefore, caregivers' autonomy to make care decisions is restricted when they are expected to make decisions on behalf of patients with limited information and conflict from other family members.

Ethical concerns at the end-of-life can also develop when caregivers do not consider patients' autonomy to make decisions for themselves. In some studies, caregivers did not consider patient preferences or perspectives because patients had reduced cognitive capacity or a terminal illness (Friedman, 1998, Bekkema et al., 2014). Some caregivers also assumed patients were unable to make the best decisions for themselves, despite being competent (Friedman, 1998, Bekkema et al., 2014). For example, in situations where patients had severe intellectual disability and/or dementia, caregivers often did not share relevant medical information with patients, excluded patients from medical discussions, and made decisions for patients because they believed they knew what was best for them (Bekkema et al., 2014, Friedman, 1998, Dreyer et al., 2009, Roman et

al., 2014, Shalowitz et al., 2006, Wagemans et al., 2010). As a result, patients' autonomy to make or contribute to decisions can be compromised.

Characteristics of the included articles are summarized in **Table 1**.

Figure 1-PRISMA Diagram



**Table 1: Characteristics of Included Articles**

Article Characteristics	No. Articles (N = 57)
<b>Year of Publication</b>	
1980-2000	5 (9%) (Banks et al., 1986; Blum, 1994; Friedman, 1998; Healy, 1998; Pratt et al., 1987)
2001-2022	52 (91%) (Aujoulat et al., 2002; Baumrucker et al., 2009; Bekkema et al., 2014; Brashler, 2006; Bute et al., 2015; Cantor, 2006; Chen, 2008; Cho et al., 2020; Cree et al., 2015; Dawson et al., 2017; Day et al., 2011; Doornbos, 2002; Dreyer et al., 2009; Finocchiaro et al., 2011; Fjelltnun et al., 2009; Germeni & Sarris, 2015; Gray et al., 2008; Hughes et al., 2002; Jankovic et al., 2011; Kebede et al., 2020; Kirk, 2007; Koenig, 2005; Kuehlmeier et al., 2012; Landau et al., 2010, 2011; Lavoie-Tremblay et al., 2012; Livingston et al., 2010; Madeo et al., 2008; Marshall & Solomon, 2003; McNeil, 2013; Norris, 2003; Özgönül & Bademli, 2022; Pérez-Cárceles et al., 2005; Petriwskyj et al., 2013; Petronio & Sargent, 2011; Petronio et al., 2004; Powell et al., 2010; Pucci et al., 2003; Robert et al., 2020; Roman et al., 2014; Roscoe et al., 2006; Shalowitz et al., 2006; Stanley et al., 2008; Tang, 2019; Tracy et al., 2004; van den Hooff & Goossensen, 2015; Wagemans et al., 2010; Wainwright et al., 2015; Wenzel Egan & Hesse, 2018; White & Montgomery, 2014; Wilkinson & McAndrew, 2008; Wynaden & Orb, 2005)
<b>Primary Country</b>	
United States of America	22 (39%) (Banks et al., 1986; Baumrucker et al., 2009; Blum, 1994; Brashler, 2006; Bute et al., 2015; Cantor, 2006; Chen, 2008; Cho et al., 2020; Doornbos, 2002; Friedman, 1998; Healy, 1998; Kirk, 2007; Koenig, 2005; Madeo et al., 2008; Marshall & Solomon, 2003; Norris, 2003; Petronio & Sargent, 2011; Petronio et al., 2004; Pratt et al., 1987; Roscoe et al., 2006; Shalowitz et al., 2006; Wenzel Egan & Hesse, 2018)
United Kingdom	10 (17.8%) (Cree et al., 2015; Gray et al., 2008; Hughes et al., 2002; Jankovic et al., 2011; Livingston et al., 2010; Powell et al., 2010; Stanley et al., 2008; Wainwright et al., 2015; White & Montgomery, 2014; Wilkinson & McAndrew, 2008)
Australia	3 (5.3%) (Dawson et al., 2017; Petriwskyj et al., 2013; Wynaden & Orb, 2005)
Canada	3 (5.3%) (Lavoie-Tremblay et al., 2012; McNeil, 2013; Tracy et al., 2004)
Netherlands	3 (5.3%) (Bekkema et al., 2014; van den Hooff & Goossensen, 2015; Wagemans et al., 2010)
Israel	2 (3.5%) (Landau et al., 2010, 2011)
Italy	2 (3.5%) (Finocchiaro et al., 2011; Pucci et al., 2003)
Norway	2 (3.5%) (Dreyer et al., 2009; Fjelltnun et al., 2009)
Ireland	1 (1.6%) (White & Montgomery, 2014)
Germany	1 (1.6%) (Kuehlmeier et al., 2012)
Romania	1 (1.6%) (Roman et al., 2014)
Greece	1 (1.6%) (Germeni & Sarris, 2015)
China	1 (1.6%) (Tang, 2019)
Belgium	1 (1.6%) (Aujoulat et al., 2002)
Spain	1 (1.6%) (Pérez-Cárceles et al., 2005)
Ethiopia	1 (1.6%) (Kebede et al., 2020)
France	1 (1.6%) (Robert et al., 2020)
Turkey	1 (1.6%) (Özgönül & Bademli, 2022)



Article Characteristics	No. Articles (N = 57)
<b>Study Methodology</b>	
Qualitative	37 (64.3%) (Aujoulat et al., 2002; Banks et al., 1986; Bekkema et al., 2014; Blum, 1994; Cantor, 2006; Chen, 2008; Cree et al., 2015; Dawson et al., 2017; Day et al., 2011; Dreyer et al., 2009; Fjelltun et al., 2009; Germeni & Sarris, 2015; Gray et al., 2008; Hughes et al., 2002; Jankovic et al., 2011; Kebede et al., 2020; Koenig, 2005; Kuehlmeier et al., 2012; Landau et al., 2010; Lavoie-Tremblay et al., 2012; Livingston et al., 2010; McNeil, 2013; Petronio & Sargent, 2011; Özgönül & Bademli, 2022; Petronio et al., 2004; Powell et al., 2010; Pratt et al., 1987; Pucci et al., 2003; Roman et al., 2014; Stanley et al., 2008; Tracy et al., 2004; van den Hooff & Goossensen, 2015; Wainwright et al., 2015; Wenzel Egan & Hesse, 2018; White & Montgomery, 2014; Wilkinson & McAndrew, 2008; Wynaden & Orb, 2005)
Quantitative	8 (14.2%) (Bute et al., 2015; Doornbos, 2002; Landau et al., 2011; Madeo et al., 2008; Marshall & Solomon, 2003; Pérez-Cárceles et al., 2005; Tang, 2019; Wagemans et al., 2010)
Case Study	4 (7.1%) (Baumrucker et al., 2009; Blum, 1994; Brashler, 2006; Roscoe et al., 2006)
Mixed Methods	3 (5.3%) (Cho et al., 2020; Finocchiaro et al., 2011; Healy, 1998)
Discussion Paper	3 (5.3%) (Friedman, 1998; Norris, 2003; Robert et al., 2020)
Systematic Review	2 (3.5%) (Petriwskyj et al., 2013; Shalowitz et al., 2006)

**Table 2:** Summary of Participant Characteristics

Participant Characteristics	No. Studies ( <i>note: Some studies reported multiple categories</i> ).
<b>Reasons for Care (patient population)</b>	
Dementia	10 (Blum, 1994; Dawson et al., 2017; Day et al., 2011; Dreyer et al., 2009; Fjelltun et al., 2009; Hughes et al., 2002; Livingston et al., 2010; Pucci et al., 2003; Tracy et al., 2004; White & Montgomery, 2014)
Mental Illness	11 (Chen, 2008; Cree et al., 2015; Doornbos, 2002; Gray et al., 2008; Jankovic et al., 2011; Lavoie-Tremblay et al., 2012; Marshall & Solomon, 2003; Özgönül & Bademli, 2022; Wainwright et al., 2015; Wilkinson & McAndrew, 2008; Wynaden & Orb, 2005)
Cancer	6 (Baumrucker et al., 2009; Finocchiaro et al., 2011; Germeni & Sarris, 2015; Kebede et al., 2020; Kirk, 2007; Tang, 2019)
Intellectual Disability	3 (Bekkema et al., 2014; Friedman, 1998; Wagemans et al., 2010)
Chronic Illness	2 (Banks et al., 1986; Roman et al., 2014)
Human Immunodeficiency Virus	1 (Aujoulat et al., 2002)
Korsakoff Syndrome	1 (van den Hooff & Goossensen, 2015)
Stroke	1 (Brashler, 2006)
Terminal Illness	1 (Shalowitz et al., 2006)
Vegetative State	1 (Kuehlmeier et al., 2012)
Covid-19	1 (Robert et al., 2020)
Not Reported	19 (Bute et al., 2015; Cantor, 2006; Cho et al., 2020; Fjelltun et al., 2009; Healy, 1998; Koenig, 2005; Landau et al., 2010, 2011; Madeo et al., 2008; Norris, 2003; Pérez-Cárceles et al., 2005; Petriwskyj et al., 2013; Petronio & Sargent, 2011; Powell et al., 2010; Pratt et al., 1987; Roscoe et al., 2006; Stanley et al., 2008; Wenzel Egan & Hesse, 2018)

<b>Participant Characteristics</b>	<b>No. Studies</b> ( <i>note: Some studies reported multiple categories</i> ).
<b>Family Caregiver's Relationship to Patient</b>	
Partners (Common law, spouses)	27 (Aujoulat et al., 2002; Blum, 1994; Bute et al., 2015; Dawson et al., 2017; Day et al., 2011; Dreyer et al., 2009; Fjellton et al., 2009; Germeni & Sarris, 2015; Hughes et al., 2002; Jankovic et al., 2011; Kirk, 2007; Koenig, 2005; Kuehlmeier et al., 2012; Landau et al., 2010, 2011; Livingston et al., 2010; Madeo et al., 2008; Powell et al., 2010; Pratt et al., 1987; Pucci et al., 2003; Roman et al., 2014; Roscoe et al., 2006; Tracy et al., 2004; van den Hooff & Goossensen, 2015; Wainwright et al., 2015; White & Montgomery, 2014; Wilkinson & McAndrew, 2008)
Children	24 (Baumrucker et al., 2009; Blum, 1994; Brashler, 2006; Bute et al., 2015; Dawson et al., 2017; Dreyer et al., 2009; Fjellton et al., 2009; Germeni & Sarris, 2015; Hughes et al., 2002; Jankovic et al., 2011; Koenig, 2005; Kuehlmeier et al., 2012; Landau et al., 2010, 2011; Livingston et al., 2010; Madeo et al., 2008; Pérez-Cárceles et al., 2005; Pratt et al., 1987; Pucci et al., 2003; Roman et al., 2014; Tracy et al., 2004; van den Hooff & Goossensen, 2015; Wenzel Egan & Hesse, 2018; White & Montgomery, 2014)
Parent	12 (Aujoulat et al., 2002; Bekkema et al., 2014; Jankovic et al., 2011; Koenig, 2005; Kuehlmeier et al., 2012; Marshall & Solomon, 2003; Özgönül & Bademli, 2022; Pérez-Cárceles et al., 2005; Roscoe et al., 2006; van den Hooff & Goossensen, 2015; Wainwright et al., 2015; Wilkinson & McAndrew, 2008)
Sibling	5 (Bekkema et al., 2014; Bute et al., 2015; Jankovic et al., 2011; Pratt et al., 1987; van den Hooff & Goossensen, 2015)
Friend	4 (Bekkema et al., 2014; Bute et al., 2015; Dawson et al., 2017; van den Hooff & Goossensen, 2015)
Grandchildren	3 (Bute et al., 2015; Powell et al., 2010; Pratt et al., 1987)
Children-in-law	3 (Dreyer et al., 2009; Koenig, 2005; Powell et al., 2010)
Brother-in-law	1 (Bekkema et al., 2014)
Grandparent	1 (Jankovic et al., 2011)
Nephew	1 (Bute et al., 2015)
Niece	1 (Bute et al., 2015)
Unspecified/Other	18 (Banks et al., 1986; Bute et al., 2015; Chen, 2008; Cree et al., 2015; Finocchiaro et al., 2011; Friedman, 1998; Germeni & Sarris, 2015; Landau et al., 2011; Lavoie-Tremblay et al., 2012; Livingston et al., 2010; Petronio et al., 2004; Powell et al., 2010; Pucci et al., 2003; Robert et al., 2020; Roman et al., 2014; Shalowitz et al., 2006; Wagemans et al., 2010)
Not Reported	13 (Cantor, 2006; Cho et al., 2020; Doornbos, 2002; Gray et al., 2008; Healy, 1998; Kebede et al., 2020; McNeil, 2013; Norris, 2003; Pérez-Cárceles et al., 2005; Petriwskyj et al., 2013; Petronio & Sargent, 2011; Stanley et al., 2008; Tang, 2019)
<b>Characteristics of Professionals</b>	
Social Workers	8 (Aujoulat et al., 2002; Bekkema et al., 2014; Brashler, 2006; Gray et al., 2008; Healy, 1998; Madeo et al., 2008; Marshall & Solomon, 2003; Tracy et al., 2004)



Participant Characteristics	No. Studies (note: Some studies reported multiple categories).
Physicians	7 (Aujoulat et al., 2002; Bekkema et al., 2014; Gray et al., 2008; Kebede et al., 2020; Pérez-Cárceles et al., 2005; Stanley et al., 2008; Tracy et al., 2004)
Nurses	7 (Aujoulat et al., 2002; Baumrucker et al., 2009; Fjellun et al., 2009; Kirk, 2007; Petronio & Sargent, 2011; Tracy et al., 2004)
Psychologists	4 (Aujoulat et al., 2002; Bekkema et al., 2014; Brashler, 2006; Marshall & Solomon, 2003)
Case Managers	2 (Chen, 2008; Tracy et al., 2004)
Management	2 (Gray et al., 2008; Lavoie-Tremblay et al., 2012)
Pharmacists	1 (Aujoulat et al., 2002)
Biologists	1 (Aujoulat et al., 2002)
Hospice Coordinators	1 (Bekkema et al., 2014)
End-of-Life Care Consultants	1 (Bekkema et al., 2014)
Volunteers	1 (Bekkema et al., 2014)
Adult Education Teachers	1 (Madeo et al., 2008)
Recreational Therapists	1 (Madeo et al., 2008)
Counsellors	1 (Marshall & Solomon, 2003)
Occupational Therapists	1 (Tracy et al., 2004)
Unspecified	1 (Aujoulat et al., 2002)
Not Reported	33 (Banks et al., 1986; Blum, 1994; Bute et al., 2015; Cantor, 2006; Cho et al., 2020; Cree et al., 2015; Dawson et al., 2017; Day et al., 2011; Doombos, 2002; Finocchiaro et al., 2011; Friedman, 1998; Germeni & Sarris, 2015; Hughes et al., 2002; Jankovic et al., 2011; Koenig, 2005; Kuehlmeier et al., 2012; Landau et al., 2011; Livingston et al., 2010; McNeil, 2013; Petriwskyj et al., 2013; Petronio et al., 2004; Powell et al., 2010; Pratt et al., 1987; Pucci et al., 2003; Robert et al., 2020; Roman et al., 2014; Roscoe et al., 2006; Shalowitz et al., 2006; Tang, 2019; van den Hooff & Goossens, 2015; Wainwright et al., 2015; Wenzel Egan & Hesse, 2018; White & Montgomery, 2014; Wynaden & Orb, 2005)

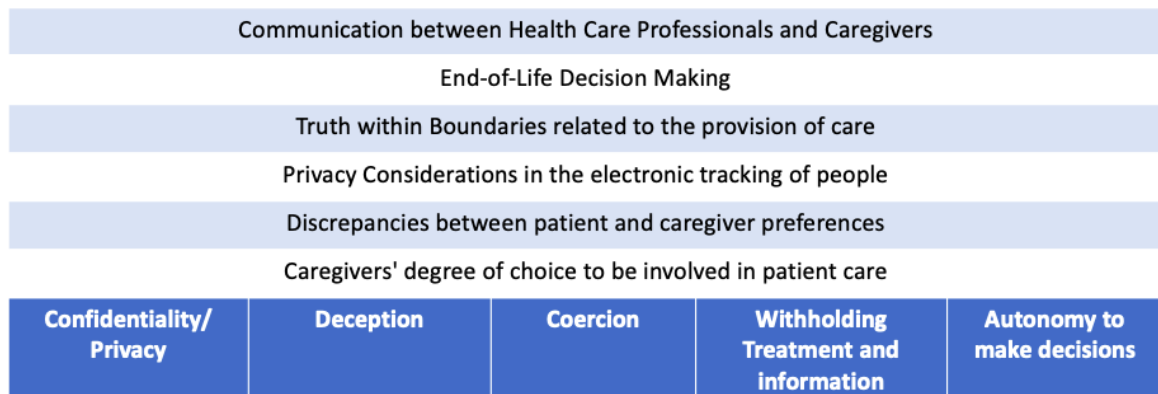


Figure 2. Core Ethical Issues and their Relation to Family Involvement in Patient Care

**Truth within boundaries related to the provision of care:** Fourteen studies (24.5%) were identified within this category. Truth within boundaries related to the provision of care occurred in the contexts of terminal illness, chronic illness, cancer, and dementia. Within this category, ethical concerns such as patient autonomy to make decisions, withholding information and treatment, deception, and coercion were commonly identified. Truth within boundaries occurred when caregivers limited the amount of information shared with patients either to protect the patient or for the benefit of the caregiver. For example, some caregivers withheld diagnosis, prognosis, and treatment information from patients due to their desire to avoid distressing the patient (Wynaden and Orb, 2005, Roman et al., 2014, Wagemans et al., 2010, Finocchiaro et al., 2011, Germeni and Sarris, 2015, Hughes et al., 2002, Pucci et al., 2003, Tang, 2019). Families who make decisions to withhold information believe that they are doing so in the patients' best interests (Özgönül and Bademli, 2022). Although the intent of a caregiver can be perceived as protecting the patient, it also becomes an ethical concern as it prevents a patient from receiving medical information about their illness (Özgönül and Bademli, 2022). Sharing health information with patients may also be influenced by culture. For example, within the context of Roman and Chinese cultures, there is a belief that telling patients their diagnosis will cause harm and that the family should be the main decision maker regarding medical treatment (Roman et al., 2014, Stanley et al., 2008).

Ethical concerns also develop when caregivers, who are expected by HCPs and patients to provide prescribed care to patients, withhold or misappropriate treatment. For example, some caregivers used patients' medication for themselves or did not comply with duties outlined in care plans (Shalowitz et al., 2006, Baumrucker et al., 2009, Kirk, 2007). In some situations, caregivers used coercion and deception when, for example, caregivers admitted patients involuntarily into healthcare institutions, requested patients to give up control of their finances, urged patients to

accept more care, and wanted patients to comply with care (Blum, 1994, Day et al., 2011, van den Hooff and Goossensen, 2015, Hughes et al., 2002, Friedman, 1998). The result was to limit patients' autonomy to make decisions. Some caregivers expressed unease and recognized that using coercion and deception may violate patients' trust (Blum, 1994). Overall, family's involvement in care can lead to ethical concerns including withholding information, withholding treatment, and using coercive and deceptive practices affecting patients' autonomy to make decisions for themselves.

**Privacy considerations in the electronic tracking of people:** Five studies (8.8%) were identified in this category. Ethical concerns, such as privacy and patient autonomy to make decisions, can occur when caregivers use electronic tracking and home monitoring systems for individuals with dementia. Some caregivers believed it was their responsibility to make the decision to use tracking devices for patients with impaired cognition (Landau et al., 2011, Landau et al., 2010). The benefits of using electronic tracking include enhancing patient safety and providing more flexible forms of care as caregivers are able to remotely monitor patients (Powell et al., 2010). Patients and caregivers both expressed concern over the impact on patients' privacy and independence due to the intrusiveness of home monitoring systems on a patient's life (Landau et al., 2010, Powell et al., 2010, Cantor, 2006, White and Montgomery, 2014). Use of electronic devices can assist caregivers with their caregiving role but can also impact patient privacy and autonomy to make decisions about their care.

**Discrepancies between caregivers' and patients' preferences:** Eight studies (14%) were identified within this category in the context of dementia, Korsakoff Syndrome, and patients in a vegetative state. Ethical concerns occur when caregivers and patients express different preferences for life sustaining treatment and living arrangements. The common concern was patient autonomy to make decisions. For example, patients and caregivers often differed in their preference for use of artificial nutrition and hydration

(Kuehlmeier et al., 2012). Decisions regarding nursing home placements can also become complicated. In one study, a caregiver experienced challenges deciding whether or not to move a patient to a nursing home (Fjellton et al., 2009). Although this was suggested as an appropriate option by the patient's nurse, the caregiver was hesitant to place the patient in a nursing home because they were being supported by the patient's pension (Fjellton et al., 2009).

In contrast, some caregivers aimed to persuade patients to accept nursing home placements even though this was not patients' wishes (Hughes et al., 2002, Fjellton et al., 2009, Wenzel Egan and Hesse, 2018). In these cases, caregivers prioritize patients' health and safety over patients' wishes (Livingston et al., 2010, van den Hooff and Goossensen, 2015, Wenzel Egan and Hesse, 2018, Norris, 2003). Likewise, when caregivers make decisions because they question patients' cognitive capacity, this limits patients' autonomy to choose between moving to a nursing home or continuing to live at home (Healy, 1998). However, caregivers also expressed guilt when their care decisions limited patients' autonomy (Wenzel Egan and Hesse, 2018). Patient autonomy to make decisions is compromised when families make decisions regarding the use of life sustaining treatment and nursing home placements that differ from patients' wishes.

**Caregivers' degree of choice to be involved in patient care:** Two studies (3.4%) were identified within this category. The ethical issue of caregivers' autonomy to decide the extent to which they want to be involved in patients' care is discussed in the stroke and dementia literature. Family caregivers discussed not always being given a choice as to whether they take on the role of a caregiver. For example, caregivers questioned whether they were truly provided a free choice to continue providing care to their loved ones beyond their ability when availability of alternative caregiving options were limited (Pratt et al., 1987). In these situations, caregivers experienced challenges deciding whether to be involved in patients' care as they must balance their own needs (e.g.,

pursuing their own goals and physical health) with the care needs of patients (Brashler, 2006, Pratt et al., 1987).

## Discussion

This review aimed to identify and synthesize ethical concerns raised in the family caregiving literature. We identified ethical concerns related to family-involvement in care, including confidentiality/privacy, deception, coercion, withholding treatment and information, and patient and caregiver autonomy to make decisions. These ethical concerns interact to influence communication between HCPs and caregivers, end-of-life decision making, truth within boundaries related to the provision of care, privacy considerations in the electronic tracking of people, discrepancies between caregiver and patient preferences, and caregiver's degree of choice to be involved in patient care. When considered together, concerns highlight overarching challenges related to information sharing in the context of privacy legislation and autonomy to make decisions about treatment and care. These issues must be considered as we aim to enhance family involvement in patient care across the care continuum (e.g., family centered care, FCC).

The importance of communication and, specifically, the sharing of personal patient information between HCPs, patients and family caregivers was notable across studies suggesting that this is an important issue. This related to communication between families and HCPs, issues related to privacy (both within the context of HCPs sharing to families and families sharing with HCPs), and decision-making regarding current and future care options. In the context of development and implementation of models of FCC where family members are formally included in the patient's circle of care, these issues need to be considered. Issues related to confidentiality have been discussed previously including differences in family opinions, cultural values, and beliefs, but also managing tensions between patients' autonomy to make decisions for themselves and accommodating family interests (Menon et al., 2020). Privacy legislation may

further constrict the information sharing between HCPs and caregivers (Hodgson et al., 2016, Barney et al., 2020). Legislation limits the sharing of information with family members in the context of adult care unless explicit patient consent exists (Hodgson et al., 2016). Information sharing, therefore, may have implications for collaborative decision-making processes that occur within different care contexts (e.g., location, condition), particularly in situations that do not recognize the involvement of family in care. FCC models are encouraged to consider information sharing as an ongoing partnership that respects patients, HCPs and families (Stolee et al., 2020) and to consider the context and implications of information sharing that may challenge effective collaboration between patients, caregivers, and HCPs. Shared decision-making and appropriate information sharing should be seen on a continuum whereby the involvement of individuals may match their cognitive abilities (Samsi and Manthorpe, 2013) and the context and nature of the decision at hand (Miller et al., 2016) (e.g., end of life care). Future research should consider an in-depth exploration of how information sharing influences decision-making over illness and caregiving trajectories for various patient populations and in the context of culturally diverse families to inform future interventions to facilitate FCC.

Our review highlighted ethical concerns related to patient autonomy to make decisions regarding end-of-life care and use of electronic monitoring. Caregivers' own autonomy was considered within their decision to provide or continue to provide care. Our review also highlighted situations in which patient autonomy may be further compromised, such as in the context of a cognitive impairment. Thus, within the context of FCC, promoting autonomy may not be applied the same way in all contexts for all patients. FCC also requires managing tensions between patients' autonomy to make decisions for themselves and accommodating family interests (Menon et al., 2020). As such, autonomy within FCC may require patients, caregivers and HCPs to consider each other's knowledge, abilities,

needs, values and preferences and how these may change over time (Edwards, 2010). Strategies to support the patient and caregiver autonomy may include the implementation of shared decision support tools, question prompt lists and training for all members of the care team (Légaré et al., 2018). The creation of advanced care directives, particularly early in the illness trajectory, may also have the potential to preserve autonomy (Chan, 2018). Future research is needed to understand the boundaries of advanced care directives in supporting autonomy within FCC, such as when they are or are not applicable (Kollisch et al., 2021).

**Limitations:** This scoping review was limited to peer-reviewed articles published in English. While the included articles were heterogeneous (i.e., care provided in different care contexts, countries, and different patient populations), the focus of these articles was not on ethical concerns. Thus, issues were identified and interpreted by the research team.

**Conclusion:** This review of 56 articles has contributed to the literature by identifying ethical concerns that can arise when family members are involved in patient care. The ethical concerns interact to influence communication and the sharing of personal health information between HCPs and caregivers; end-of-life decision making; truth within boundaries related to the provision of care; privacy considerations in the electronic tracking of people; discrepancies between caregiver and patient preferences; and caregiver's degree of choice to be involved in patient care. It is important for HCPs, caregivers, and patients to be aware of these issues to enhance the care of patients and, ultimately, the health and wellbeing of patients and caregivers. These findings build upon the universal model of FCC proposed by Kokorelias et al (2019) by adding "ethical concerns related to family involvement in patient care" to the discussion. This review identified some key ethical concerns that need to be addressed in future research to enhance the development and implementation of models of FCC.



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#### APENDIX A

#### Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
<b>TITLE</b>			
Title	1	Identify the report as a scoping review.	Title page
<b>ABSTRACT</b>			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	1
<b>INTRODUCTION</b>			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	2
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	2
<b>METHODS</b>			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	3
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	3
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	3-4
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	Appendix B
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	4
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	4
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	4

Critical appraisal of individual sources of evidence§	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	4
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	4

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
<b>RESULTS</b>			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	Figure 1
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	Tables 1 & 2
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	N/A
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	Tables 1 & 2
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	5-11
<b>DISCUSSION</b>			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider their relevance to key groups.	Figure 2
Limitations	20	Discuss the limitations of the scoping review process.	11-12
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	14
<b>FUNDING</b>			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	15

JBIC = Joanna Briggs Institute; PRISMA-ScR = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews. \* Where *sources of evidence* (see second footnote) are compiled from, such as bibliographic databases, social media platforms, and Web sites. † A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g., quantitative and/or qualitative research, expert opinion, and policy documents) that may be eligible in a scoping review as opposed to only studies. This is not to be confused with *information sources* (see first footnote). ‡ The frameworks by Arksey and O'Malley (6) and Levac and colleagues (7) and the JBI guidance (4, 5) refer to the process of data extraction in a scoping review as data charting. § The process of systematically examining research evidence to assess its validity, results, and relevance before using it to inform a decision. This term is used for items 12 and 19 instead of "risk of bias" (which is more applicable to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used in a scoping review (e.g., quantitative and/or qualitative research, expert opinion, and policy document).

From: Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMA ScR): Checklist and Explanation. *Ann Intern Med.* 2018;169:467–473.

#### APPENDIX B

##### Sample Search Strategy

The search strategy was conducted using the following keyword search: ((ethic\* OR privacy OR confidential\* OR PHIPPA) AND ("family-centered care" OR "family-centered care model\*" OR "family care model" OR care\* OR "care giver\*" OR "care-giver\*" OR "care partner\*") NOT child\*).