



The decision partner in healthcare decision-making: A concept analysis

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ABSTRACT

Background: The decision partner concept emerged to describe someone who contributes to healthcare decision-making with a patient. There is a need for greater precision and consensus surrounding its conceptual definition and use in broader populations.

Objective: To define and describe the decision partner concept within the context of healthcare decision-making.

Design: A concept analysis.

Data sources: We searched the following databases for articles published between 1990–2017: PsychINFO, PubMed, Embase, and CINAHL. We included qualitative, quantitative, or mixed methods studies that used the term *decision partner* in the context of healthcare decision-making.

Methods: We applied the Walker and Avant method to identify the antecedents, attributes, related concepts, consequences, and empirical referents of the concept, with major themes identified.

Results: From the 112 articles included in this concept analysis, 6 defining attributes of decision partner were identified: (1) has a relationship with the patient, (2) demonstrates a willingness to participate in decision-making, (3) articulates a clear understanding of both the patient's health condition and the decisions that must be made, (4) demonstrates decision-making self-efficacy; (5) exemplifies an emotional capacity to participate in decision-making, and (6) willing to fulfill several supportive roles including patient advocate and the "hub of information".

Conclusions: A unifying definition and discussion of the decision partner concept has been developed. Our findings: (1) offer insights into refining the concept across various diseases and healthcare encounters, (2) contribute to developing theoretical models and empirical research to refine antecedents, attributes, consequences, (3) serve as a foundation to develop instruments to measure the concept and (4) highlight the need to design interventions that include and support decision partners in healthcare decision-making.

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What is already known about the topic?

- We know that family and friends are often engaged in decision-making within healthcare contexts.
- Researchers and clinicians worldwide recognize the relevance and contributions of shared decision-making in healthcare encounters.
- The presence, inclusion, and active engagement of family members in healthcare decision-making is an area of practice

that is yet to be fully integrated and supported by healthcare professionals.

What this paper adds

- This paper adds to the body of knowledge by providing conceptual understanding of the term *decision partner* based on multiple defined attributes, antecedents, and consequences.
- Clarification of the definition of decision partner can help researchers better distinguish it from similar concepts.
- The reader is introduced to the decision partner concept to better describe the role of family in the context of healthcare decision-making across various diseases and medical encounters.

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1. Introduction

Healthcare decision-making occurs within the context of wider social networks and commonly extends beyond the patient and the healthcare provider relationship. However, healthcare decision-making research has previously focused primarily on clinical encounters with providers (Schumm et al., 2010; Ballard-Reisch and Letner, 2003). Although patient autonomy, the capacity to make decisions independently, is increasingly recognized and valued in health care, patients do not always make decisions in isolation. In healthcare encounters, patients often involve and rely on family members in the decision-making process, particularly because an illness affects not only the patient, but also imposes changes in the whole family system (Northouse, 2012). For the purposes of this article, ‘family’ is defined as any individual who plays a significant role in another person’s life; this can include intimate partners, friends, spouses, or relatives. We know that family and friends are often engaged in decision-making within healthcare contexts; and researchers and health care providers worldwide recognize the significance and relevant contributions of shared decision-making in healthcare encounters (van Nistelrooij et al., 2017; Laidsaar-Powell et al., 2016a). However, there is a relatively small body of literature on how family members participate in decisions (Laidsaar-Powell et al., 2013), resulting in a need for further work to understand the role of family in decision-making and the ways in which those relationships influence the patient’s own decision making, both inside and outside the medical visit (Clayman et al., 2017a, 2017b). While much of the shared decision-making literature has focused on the provider-patient relationship (Bélanger et al., 2011; Clayman et al., 2017a, 2017b), it has also discussed the role of family in decision-making as illness advances (Légaré et al., 2011). In the face of serious illness, these family members may act as surrogate, proxy or substitute decision-makers in shared decision-making (Washington et al., 2016; Li et al., 2018). However, there is a critical importance to examine and describe family members in the context of shared decision-making for any health-related decision and not solely in the context of serious illness.

From a bioethical perspective, the principle of relationality denotes respect for human beings insofar as they are essentially related to other human beings. For relationships to flourish, everyone involved should feel respected (DuBois, 2007). Understanding the structure and enactment of decision-making within family interactions can provide insight into how individuals and/or family members contribute to decision-making and value autonomy and self-determination in combination with collective family actions (Trees et al., 2017; Laidsaar-Powell et al., 2017). Decision partners are clearly important in gathering information and supporting patients’ decisions (Wenzel et al., 2015; Jones et al., 2018), but central interactions and key processes are not clearly understood (Zeliadt et al., 2011). Although the “decision partner” term has been applied in the literature (Clayman et al., 2017a, 2017b; Jones et al., 2018; Wenzel et al., 2015), the work and accompanying challenges of decision partners are typically subsumed under ‘care partners’ (Bennett et al., 2017) or ‘caregivers’ (Bastawrous, 2013), concepts that have also suffered from ambiguity and that require clarification. Understanding the decision partner role in decision-making is also essential to meet patients’ needs and provide effective decision support (Clayman et al., 2017a, 2017b). Clear theoretical and operational definitions are needed to effectively target this important group. To clarify the terminology and to facilitate further study to address this gap, we applied concept analysis to define and detail these decision partners: family, close friends, or others engaged in healthcare decision-making with the patient. The results of our concept analysis are intended to enhance understanding of the concept and support the development of theories and future research.

2. Selection and purpose of the concept analysis

The first step in concept analysis is the selection of a concept to be defined and clarified (Wählin, 2017; Waltz et al., 2010). Understanding the concept of “decision partner” is critically important, particularly as patients with varying health conditions and medical encounters frequently make healthcare decisions and often rely on others for support. These family members and friends have been referred to and studied in many ways such as caregivers, care partners, and companions, but more efforts must be made to address their roles and unique contributions in healthcare decision-making. Currently, there is a noticeable absence and lack of a clear definition of the decision partner concept as well as a diffuse understanding in the literature.

The second step of concept analysis is to determine its purpose. A concept analysis provides an initial introduction to reveal the state of the science regarding a concept and offers a method to identify the shared meaning of related concepts, explain why those meanings have been developed, and describe how a distinct concept can be applied in real-life contexts. Through a rigorous process, our concept analysis contributes to a body of knowledge to identify, distinguish, validate, and define a concept as well as to clarify overused terms with ambiguous meaning. We aimed to identify antecedents, attributes, consequences, and a present definition of the decision partner concept that will add to the understanding of its use in healthcare decision-making.

3. Methods

3.1. Concept analysis method

For the concept analysis, we applied the Walker and Avant method (1995), which includes eight steps, has had widespread use (Duncan et al., 2007), and uses a systematic approach to clarify concepts (Rodgers et al., 2018). Fig. 1 presents the steps of this method to guide the examination of the function and structure of the decision partner concept.

3.2. Data sources

A search of relevant health and medical databases, including PsychINFO, PubMed, Embase, and CINAHL, was performed to construct conceptual and operational definitions of defining characteristics of the decision partner concept. Articles from the search focused on persons outside of healthcare professionals with whom patients make decisions about care. Inclusion criteria

The Eight Steps of a Concept Analysis

1. Select a concept.
2. Determine the aims.
3. Identify all uses of the concept.
4. Determine the defining attributes.
5. Construct a model case.
6. Construct borderline, related, contrary, and model cases.
7. Identify antecedents and consequences.
8. Define empirical referents.

Fig. 1. Steps of the Walker and Avant method (2005) for a concept analysis.

included: articles published from 1990 to 2017, case studies, systematic reviews, original research, and secondary analyses in peer-reviewed journals, and contained the term *decision-making* or other related terms, such as *decision-making* or *making decisions*, in the context of healthcare or treatment decision-making. Research designs included mixed-methods, quantitative, qualitative, or review papers in English. We screened titles and abstracts of the resulting literature to eliminate articles that did not meet the inclusion criteria, reviewing full-text articles to assess contextual information congruent with the concept. References were reviewed for additional sources of the concept. Results from the literature search are presented in Fig. 2.

4. Results

4.1. Definition of the concept

While there are many definitions of the word *decision*, we chose to adopt its definition as “a conclusion or resolution reached” (Noone, 2002). *Decision-making* is the “cognitive process of reaching a decision” (Tariman et al., 2012), and often involves the weighing of available treatment, benefits and risks, uncertainty, and associated burdens (Siminoff, 2013; Palmer-Wackerly et al., 2017). *Partner* is defined by Merriam-Webster Dictionary (2017) as “one associated with another especially in an action,” “one that shares,” “a member of a partnership.” *Partnership* refers to “a shared commitment, where all partners have a right and an obligation to participate” (Ying and Loke, 2016). There is a growing emphasis to encourage patients to partner with healthcare providers and to be actively involved in decisions about their care (Gallant et al., 2002). In addition, there has been a growing need to recognize and include third-party members, such as family members, in this partnership. The combination of these definitions form to create the decision partner concept, which describes someone who shares in the act of decision-making with another person.

4.2. Use of concept in the existing literature

The third step in the concept analysis is to identify the uses of the concept in literature sources. To date, the specific ‘decision partner’ concept has not been commonly used or consistently described in the literature, as shown in Fig. 3. Wenzel et al. (2015) introduced the concept following an analysis of qualitative interviews that revealed that in addition to family, non-family members were integrally involved in decision-making about clinical trial participation for African American cancer patients. Distinct from Wenzel’s initial usage, Clayman et al. (2017a,b) expanded the definition beyond clinical trial decision-making to encompass all healthcare-related decisions. Of note, not all family



Fig. 3. Decision partner publications.

members are engaged in healthcare decision-making; terms such as *caregivers* should not be confused with decision partners as essential contributors to patient decisions (Clayman et al., 2017a, b). In the current literature, a decision partner has most frequently been referred to as a significant other (spouse), child, sibling, friend, or close relative of the patient (Clayman et al., 2017a,b; Wenzel et al., 2015).

4.3. Defining attributes

The fourth step in the concept analysis is to determine the defining attributes. These are characteristics that help to differentiate the concept from related concepts (Bennett et al., 2017). Based on literature and expert review/input, six key defining attributes were identified for the concept of decision partner: (1) has a trusting relationship with the patient, (2) demonstrates a willingness to participate in decision-making, (3) articulates a clear understanding of both the patient’s health condition and the decision that must be made, (4) demonstrates decision-making self-efficacy, (5) exemplifies an emotional capacity to participate in decision-making, and (6) is willing to fulfill several supportive roles as needed.

4.3.1. Has a trusting relationship with the patient

The first attribute of this concept is that one must have a trusting relationship with the patient. Thus, there is an assumption that the decision partner has perceived knowledge of the patient and can be either a family member, close friend, spouse or cohabitating partner, or significant other to the patient. In the literature, the concept of trust has been shown to be the dominant feature of caregivers’ relationships with patients and is central to the caregiving dyad (primary caregiver and the care recipient) (Ray and Street, 2011), and implies a confidence in another individual based on past experiences (Meize-Growchowski, 1984). Trust is integral to building healthy social capital and is the basis of effective family and community relationships (Coleman, 1988; Putnam et al., 1993; Gonzalez, 2017), making it an appropriate attribute of decision partners.

4.3.2. Demonstrates a willingness to participate in decision-making

The second attribute of the concept is that one is willing to be a part of the healthcare decision-making process. The decision partner must have a willingness to participate, question, challenge, and seek information. He or she does not necessarily need to be physically present or near the patient, and instead should be available and accessible. A willingness to participate in decision-making is crucial. Not all family members are willing to help patients; many prefer to distance themselves from the patient in the context of health care (Vargas-Huicochea et al., 2018).

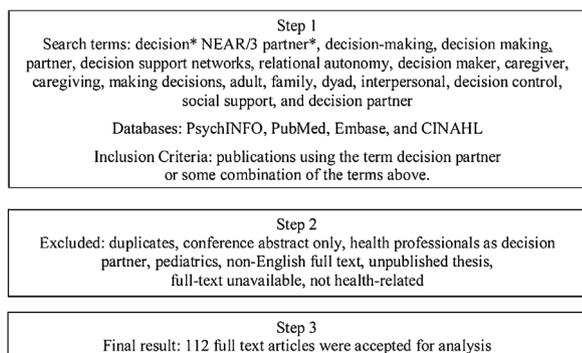


Fig. 2. Literature Review Methods and Results.

4.3.3. Articulates a clear understanding of both the patient's health condition and the decision that must be made

The third attribute of the concept is that one must be able to articulate a clear understanding of both the patient's health condition and knowledge about the decision that must be made. He/she must bring personal knowledge on the suitability of different treatments for the patient's circumstances and preferences (McGinnis et al., 2013), and provide the doctor with information about the patient's medical history or symptoms (Wolff et al., 2015). This understanding allows the decision partner to engage in decision-making fully and responsibly in a way that optimizes the relationship, demonstrating the decision partner's importance to the patient.

4.3.4. Demonstrates decision-making self-efficacy

The fourth attribute of the concept is to demonstrate self-efficacy in decision-making. It can be difficult to sort through an overwhelming amount of information and identify the facts that are relevant to the choice in question (Rid and Wendler, 2010). Therefore, decision partners should exhibit decision-making self-efficacy in their role. Self-efficacy refers to individuals' beliefs and confidence regarding their capability to produce designated levels of performance that exercise influence over events (Lopez and Guarino, 2013; Nolan et al., 2009). The Surrogate Decision-Making Self-Efficacy Scale (SDM-SES) describes components of decision-making self-efficacy: (1) knowing when to make decisions, (2) ability to obtain information to make informed decisions, (3) ability to weigh risks and benefits of treatment options, (4) ability to make the best treatment decisions, and (5) knowing what treatment options the individual patient would select (Lopez and Guarino, 2013). When considering these components of decision-making self-efficacy, one should acknowledge that a decision partner is not the inherently same as a surrogate decision-maker, and this distinction is further described in more detail. Overall, decision-making self-efficacy implies an assertiveness and confidence to discuss the decision options with the patient and care team.

4.3.5. Exemplifies an emotional capacity to participate in decision-making

The fifth attribute includes having emotional capacity to participate in decision-making (Zeliadt et al., 2011). A major factor in what family members want to hear or can absorb is, of course, their emotional state (Billings, 2011). Shock and denial are common reactions to distressing information, even when family members think they are prepared (Hebert et al., 2006). In decision-making, there can be emotional discomfort, including intrapersonal tensions and inner emotional conflicts (Jezewski, 1994), especially when one must make 'life or death' decisions (Schenker et al., 2012). Therefore, decision partners must exhibit traits of emotional readiness to participate in decision-making.

4.3.6. Willing to fulfill several supportive roles to aid in decision-making as needed

The sixth attribute of the concept is willingness to fulfill a variety of supportive roles as needed in the decision-making process. Roles may include serving as the patient advocate by defending the patients' interests, providing useful information and asking questions to know more about the treatments (e.g., alternatives, potential benefits/consequences) (Lamore et al., 2017). The decision partner may also serve as the 'hub of information' for the patient, meaning that he/she gathers information about a decision that must be made as well as obtains shared information and knowledge about the patient (Reeves et al., 2015). This role also entails obtaining the patient's opinions, expectations, experiences, and providing individually adapted information/knowledge (Eldh et al., 2004; Henderson, 2002;

Sainio et al., 2001; Sainio and Lauri, 2003; Tutton, 2005; Sahlsten et al., 2008), acting as a 'messenger' or 'middleman' (Laidsaar-Powell et al., 2016c), and translating and passing on information to other family members (Quinn et al., 2012) who are present or outside of the medical encounter. The role may also include summarizing the information given by the clinician, and repeating or filtering information (Lamore et al., 2017; Laidsaar-Powell et al., 2016b, c), and acting as a surrogate decision-maker or translator (Reeves et al., 2015).

4.4. Model, borderline, and contrary cases

To contribute to the decision partner concept analysis, we present model, borderline, and contrary cases as examples of the concept. These case examples provide a better understanding of the concept, given its multiple defining attributes.

4.4.1. Model case

A model case example is one that includes all defining characteristics of the concept. For instance, Lee, a 48-year-old single father of two, was recently diagnosed with cancer and has an appointment with his oncologist. Sarah, his co-worker and close friend, lives nearby and often accompanies Lee on his medical visits. When she is not physically present, Sarah engages in phone calls during the medical encounter and regularly talks with Lee to discuss healthcare decisions. In her role as a decision partner, Sarah provides the medical team with detailed information about his medical history and weighs in about different treatment options. Sarah knows Lee well, and they have a trusting relationship. She helps him to process information, discusses the perceived risks and benefits, and provides support and encouragement. She asks the care team relevant questions and communicates with his family members to update them on his care.

4.4.2. Borderline case

A borderline case has some but not all the concept attributes. For instance, Jim is 65 years of age and was admitted to the hospital following an acute stroke. After discharge, Jim appointed his adult son Jarrett as his medical power of attorney. Jarrett lives across the country and talks to his father a few times a year. They have a moderately good relationship, although they have been estranged. Jarrett often feels as though he has insufficient knowledge to make healthcare decisions with his father and the care team. Under stressful events, Jarrett is emotionally withdrawn and has difficulty coping with his father's health condition and the stress associated with decision-making. This case lacks vital attributes of a decision partner, including a willingness to fulfill supportive roles as needed. Jarrett also lacks emotional capacity to make healthcare decisions, does not have decision-making self-efficacy, and lacks a clear understanding of his father's health condition and the decisions that must be made.

4.4.3. Contrary case

A contrary case is one where the concept is used contrary to the identified attributes of a decision partner. Stacy, a 39-year old female patient, was recently admitted to the hospital following a risky cardiac procedure. After the procedure, Stacy faced several medical complications, leaving her in critical condition. Stacy does not have an advance directive or a surrogate decision-maker to provide documentation about her care preferences in the event that she is unable to do so herself. She has been assigned a court-appointed legal guardian, Larry, for her health-related matters. Larry makes healthcare decisions, provides consent to health-related decisions, and is engaged in communication with the care team though not a decision partner with Stacy. As neither a friend nor family, Larry knows very little about Stacy's medical history, social history, and current health

condition, nor does he communicate regularly with her family to better understand her goals of care. With the healthcare decisions that must be made, it is important to discern whether Larry has adequate information to make these decisions.

4.5. Related concepts

A related concept is identified as a concept related to the decision partner concept that does not exhibit all the defined attributes. Table 1 provides the commonly shared attributes between decision partners and other related concepts.

4.5.1. Decision-support person, decision-support networks, partner decisional support

Decisional support is defined as social support given and received during a decision-making context (Krieger, 2014; O'Connor, 2006; Milata et al., 2018). More specifically, decision-support persons, decision-support networks, or partner decisional support are inter-related and are often seen in the literature as family and friends who contribute to treatment decisions made by patients and considered to be both important and influential (Wallner et al., 2017). Palmer-Wackerly et al. (2017) found that partner decisional support may partially mediate the relationship between healthcare provider support and patient decision-making satisfaction (Hobbs et al., 2015). Decisional support is different from other definitions of social support that focus on the quantity, frequency, structure, and availability of perceived social support (Goldsmith, 2004; Palmer-Wackerly et al., 2017). These related concepts differ in that decision partners are involved more broadly in healthcare decisions, not solely in treatment decision-making.

4.5.2. Carer

Similar to decision partners, carers can facilitate the process of deliberation by obtaining information about treatments, discussing information with the patient, eliciting information from clinicians, and acting as sounding boards for the patient to help stimulate thinking about treatment decisions and processes behind the scenes (Hubbard et al., 2010). Unlike decision partners, carers have been described as making patient-related decisions based upon assumptions rather than confirming the current choice of the person directly (Miller et al., 2016). Their primary role, however, is not related to decision-making, and in many cases, the extent of their involvement in decision-making is dependent on individual members of the

clinical staff (Walker and Dewar, 2001; Stomski and Morrison, 2018; Hubbard et al., 2010). In the literature, carers have been largely defined as those who provide assistance (Bennett et al., 2017). They often provide the majority, if not all, of the care for a person who is unable to independently manage his/her own care and activities of daily living (ADLs) (Bennett et al., 2017). Their role can include supporting patients in their medication-taking; they also perceive themselves as voicing patients' opinions when they are not well enough to speak for themselves (Harris et al., 2017). Carers have also been described as "hope carriers"—as those who remain hopeful even when those they are caring for feel hopeless (Bradley and Green, 2018; Marshall et al., 2013).

4.5.3. Caregiver

Similar to a carer, a caregiver is a person who has a close relationship with the patient and provides assistance with the coordination of care, symptom management, disability, mobility, medications, and dressing (Lim & Zebrack, 2004; Bennett et al., 2017). Caregivers have a broader scope of responsibility than decision partners, who focus only on healthcare decision-making. For example, Sakanashi and Fujita (2017) described how engagement in healthcare decision-making was one dimension of caregivers' empowerment.

4.5.4. Care partner

The defining characteristic of the care partner concept is the existence of a person with a health condition requiring some assistance with healthcare needs (Bennett et al., 2017). The term *care partner* recognizes the interdependent and often reciprocal relationship between two or more persons who enact caring roles towards one another (Womack et al., 2016). Care contexts range from acute medical needs to long-term and end-of-life care (Bennett et al., 2017). Care partners are predominantly family members, frequently the spouse, cohabitating partner, or persons in a romantic relationship with the patient (Bennett et al., 2017; Rini et al., 2011; Manne et al., 2012), and refer to individuals who function in unpaid or informal roles (Womack et al., 2016). They provide ADL support to high-level care, assist with healthcare information facilitation, medical appointment coordination, hospital care assistance, monitoring vital signs, home care assistance, coordination of community and government assistance, coordination of family member involvement, administration of medications, and transport (Bennett et al., 2017). The decision partner's

Table 1
Attributes of Decision Partners and Other Related Concepts.

Attributes		Has a trusting relationship with the patient.	Demonstrates a willingness to participate in decision making.	Articulates a clear understanding of both the patient's health condition and the decision that must be made.	Demonstrates decision-making self-efficacy.	Exemplifies an emotional capacity to participate in decision-making.	Willing to fulfill several supportive roles to aid in decision-making as needed.
Related Concepts	Decision partner	X	X	X	X	X	X
	Decision support person	X	X	X	X	X	X
	Carer	X					X
	Caregiver	X		X			X
	Care partner	X					
	Study partner	X	X	X	X	X	X
	Close other	X					X
	Surrogate or proxy decision maker	X	X	X	X	X	X
	Accompanying person or companion						X

role has been included in the broader concept of care partners (Bennett et al., 2017).

4.5.5. Study partner

Previous investigators have used the term *study partner* to refer to family members, friends and others who have participated in patients' decision to enroll in a clinical trial, noting that some study partners became study participants themselves (Black et al., 2014; Karlawish et al., 2008). Researchers have described the role of a study partner as an informant for these patient-subjects, others who have enrolled in a clinical trial and serve as a decision-maker or surrogate for patient-subjects who lack decisional capacity or are cognitively impaired (Black et al., 2014; Grill et al., 2012). Their responsibilities include managing the logistics of study participation and providing comfort and encouragement for the patient-subject (Black et al., 2014). While decision partners are involved in a wider range of healthcare decisions, study partners specifically focus on clinical trial-related decisions and have been involved in decision-making with patients with cognitive impairments.

4.5.6. Close other

Close others are individuals such as a partner, family, and friends who patients seek out for advice and comfort (Rini et al., 2011). In other literature, close others have been referred to as romantic partners (Etcheverry and Agnew, 2008), family and friends (Hughes and Dunn, 2002), and close friends (Rosa and Gutches, 2011; Acar-Burkay et al., 2014). Close others differ from decision partners because their role does not explicitly encompass decision-making.

4.5.7. Surrogate decision-maker, proxy decision-maker, or substitute decision-maker

Surrogates are typically family members entrusted with the authority to make healthcare decisions for decisionally-incapacitated patients, and patients who are too ill (Schenker et al., 2012), unable to express their treatment preferences (Majesko et al., 2012), have progressive cognitive impairment (Elliott et al., 2009; High and Rowles, 1995), and those who are dying (Dionne-Odom et al., 2015). Surrogates/proxy or substitute decision-makers differ from decision partners in that they make decisions when the patient is unable to speak for themselves. The surrogate/proxy or substitute decision-maker is appointed by the patient and act when the patient is not competent or unable to make decisions. They are expected to make decisions that approximate as closely as possible the choices patients would make were they able (Beauchamp and Childress, 2012; Dionne-Odom et al., 2015; Winter and Parks, 2008). Therefore, a well-prepared surrogate will have had conversations with the patient about their wishes and may also have documentary guidance from the patient and legal authority. In contrast, the decision partner is not likely a legally appointed role and also operates when the patient is competent.

4.5.8. Accompanying person or companion

An accompanying person (AP) is defined as a family member or close relative who is present in a clinical consultation when information is shared between doctor and patient (Lee et al., 2018; Andrades et al., 2013). An AP has also been described elsewhere (Ekwall et al., 2009), in the context of emergency room visits, as the individual who plays a vital role in delivering psychosocial support to the patient. The primary role of an AP is to be a patient advocate (Botelho et al., 1996). Similar to an AP is the term *companion*. Companions accompany patients to the medical visit and can help patients provide physicians with essential medical history as well as reinforce, verify, and augment patients' statements (Street and Gordon, 2008; Clayman et al., 2017a,b). Companion behaviors have been broadly categorized in relation to enhancing patient

autonomy: (1) facilitating doctor understanding, (2) facilitating patient understanding, (3) facilitating patient involvement (Wolff et al., 2015). In comparison, the companion or AP may or may not be involved in decision-making, while decision partners are involved. Predominantly, their role is to be a supportive physical presence for the patient, differing from decision partners who may or may not be physically present.

4.6. Identification of antecedents and consequences

The seventh step in the concept analysis is the identification of antecedents and consequences (Walker and Avant, 2011). Antecedents—factors that are required for the concept to occur and exist (Bennett et al., 2017)—are both practical and behavioral, spanning different health conditions and diseases. Alternatively, consequences are presented as events or incidents that occur as a result of the occurrence of the concept (Walker and Avant, 2005). Introducing and implementing this concept can impact the way in which healthcare systems include others in healthcare decision-making and recognize their unique contributions. Fig. 4 describes the antecedents and consequences for the concept.

4.6.1. Consequences

4.6.1.1. *Consequences.* The consequences of introducing the decision partner concept include:

4.6.1.1.1. *Broad enough to include non-family decision partners.* The decision partner concept is broad enough to include family and non-family decision partners because healthcare decisions will undoubtedly affect their lives as well. Hardwig (1990) argued that there is no way to detach the lives of patients from the lives of those who are close to them. Family is described as “those who are close to the patient,” and often includes close friends and companions, recognizing that the word “family” has many meanings (Gregory, 2004).

4.6.1.1.2. *Potential confusion about whether this concept refers to health care providers or to professional caregivers.* There is potential confusion about whether this concept refers to or can also include clinicians in addition to lay persons. For instance, information-giving has been an essential part of the nurse's role in clinical practice, as has promoting patient autonomy and advocacy (Tariman and Szubski, 2015). However, it is important to note that in shared decision-making, clinicians such as health care providers can partner with patients, but that does not mean that they are decision partners. Some might question why, particularly when talking about shared decision-making, health care providers cannot be considered “decision partners.” While health care providers are increasingly prepared to integrate patient values and goals into their plan for treatments and care, some patients with serious illness worry about maintaining their relationship with their provider (Johnson et al., 2007) and others may tend to defer to the health care provider based on the power differential between the provider and the patient (Gulbrandsen et al., 2016). Therefore, the relationship between a health care provider and the patient is not one based on truly equal and intimate knowledge, emotion, and understanding. Patients often turn to others for decision support. Non-provider family and friends may have a more nuanced understanding of the patient's preferences and goals (Kim et al., 2018) and can therefore more readily serve as equal partners in the decision process. Furthermore, health care providers are usually not legally allowed to make health-related decisions on the part of their patients, even though well-developed and trusting relationships between the patient and health care provider may occur over time.

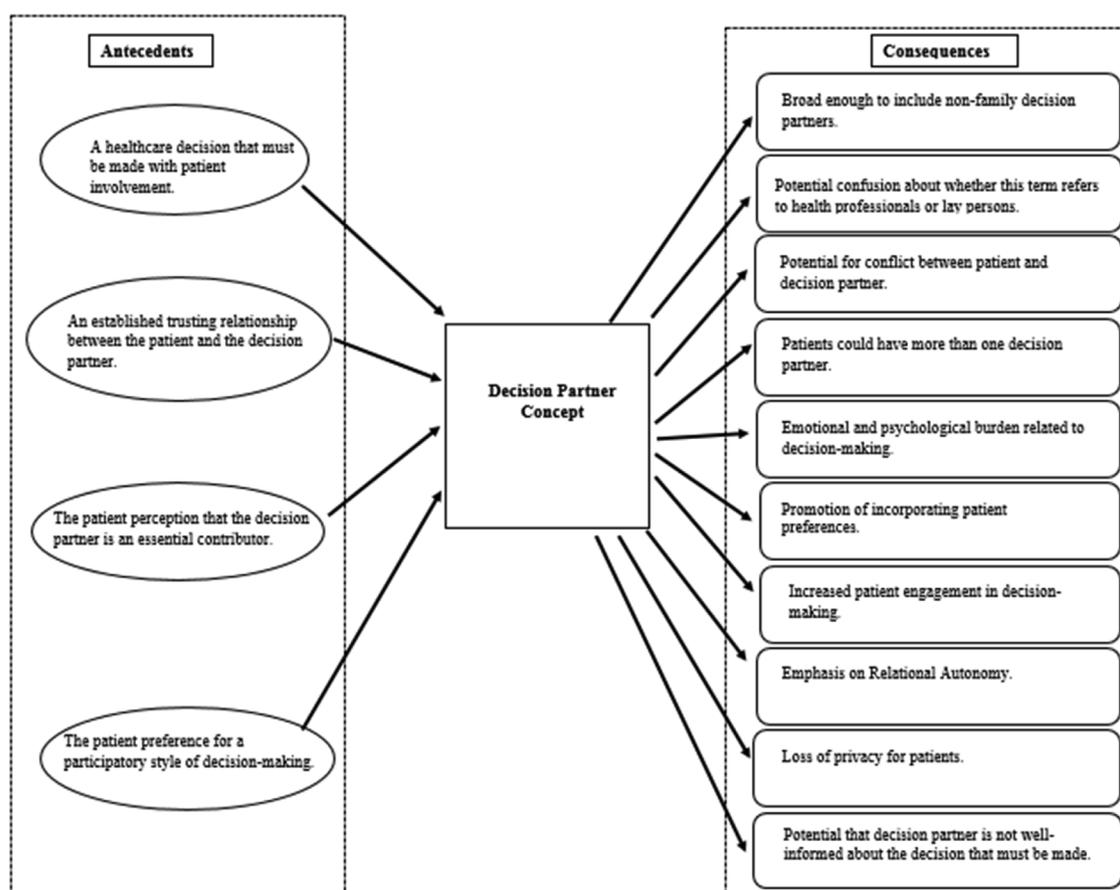


Fig. 4. Decision Partner Concept Antecedents and Consequences.

4.6.1.1.3. *Potential for conflict between patient and decision partner.* Although the decision partner helps the patient make decisions and provides emotional comfort and psychological support (Lin et al., 2017), there are instances when disagreement can arise between the patient, decision partner, and clinician. When decision partners are present, there is potential for discordant views. Individuals may place different values on different outcomes related to the decision or may enter a clinical consultation with different goals (Lee et al., 2018). They may also serve as a negative influence on the patient's decision-making (Rini et al., 2011). Certain behaviors may also be exhibited including nagging, trying to take control of the decision, or acting angry or disapproving. Decision partners can also set and promote their own agendas (Street and Gordon, 2008; Heid et al., 2016). A study investigating the full "triad" of patients, oncologists, and caregivers in cancer treatment decision-making found that patients, caregivers, and oncologists have significantly different preferences about both treatment decisions and the decision-making process. Triad members frequently disagreed about the "correct" treatment choice (LeBlanc et al., 2018). These divergent opinions (Rini et al., 2011), values and priorities could counter patients' autonomy and best interests (Ho, 2008); the resulting decisions may not accurately reflect patient's values and result in discordant preferences (Vig et al., 2007; Schenker et al., 2012; de Boer et al., 2015; Shin et al., 2015).

4.6.1.1.4. *Patients may have more than one decision partner.* Although existing literature tends to include single decision partners, this tends to be a limitation of research and analytic methods. Families often have multiple decision-makers rather than one primary

decision-maker (Quinn et al., 2012); each person may play a different role in the decision-making process. Subsequently, the need to address the wishes of multiple family members may create complexity (Parks et al., 2011), thereby making decision-making more difficult (Schenker et al., 2012). Multiple decision partners may result in different individuals asking many questions (Coats et al., 2018), requiring the medical team to divide their attention between the patient and decision partners. Recognizing and understanding the roles of multiple decision partners during critical decision-making is important to promote effective interaction and consensus among family members and to reduce conflict among family and clinicians (Quinn et al., 2012).

4.6.1.1.5. *Emotional and psychological burden related to decision-making.* The decision partner concept can also result in increased emotional and psychological burdens for the patient, clinician, and decision partner. The patient may report emotional and psychological burdens about involving a third-party, an additional person, in the decision-making process as well as express feelings of not wanting to disappoint the decision partner. Though very seldom, clinicians may recognize decision partners as 'important', 'essential', 'critical', or 'imperative' (Laidsaar-Powell et al., 2016a), but challenges can arise when they become controlling, dominant, manipulative, or requesting non-disclosed information. Decision partners may feel burdened (Wendler and Rid, 2011; Braun et al., 2009; de Boer et al., 2015) and stretched beyond their capacity (Holroyd-Leduc et al., 2016). Decision partners may also feel a sense of grief, anxiety, stress, guilt as well as doubt regarding whether they had made the right decisions (Wendler and Rid, 2011). In addition, they may find

difficulty in making decisions under a time pressure (de Boer et al., 2015). It is important to recognize these emotional and psychological burdens as related to decision-making.

4.6.1.1.6. Promotion of incorporating patient preferences. The presence of decision partners may enhance review of patient preferences, goals, and values for healthcare decisions. They may help to prioritize goals of care in alignment with the patient's values and preferences (de Boer et al., 2015), relay the patients' questions and concerns to the clinicians and vice versa (Lamore et al., 2017; Lin et al., 2013), and assist when patients are distressed (Lamore et al., 2017; Lin et al., 2017). Their presence may consist of helping patients in seeking, organizing, and processing information for health decisions, including finding a healthcare provider, receiving advice about treatment, and describing symptoms to providers (Krieger et al., 2015; Siminoff et al., 2006; Palmer-Wackerly et al., 2017).

4.6.1.1.7. Increased patient engagement in decision-making. The presence of decision partners can result in increased patient engagement in decision-making. Family involvement in patient care enhances patient's autonomy (Shin et al., 2013; Clayman et al., 2017a,b) and has been associated with greater question-seeking, less passive agreement with physician information, less social talk, and more orienting statements (Wolff et al., 2015). Particularly for vulnerable patient populations such as those who are older, less literate, mentally or cognitively impaired, who have sensory or functional deficits, or who must manage complex treatment regimens, family involvement promotes and supports patient engagement (Wolff et al., 2015; Katon, 2008).

4.6.1.1.8. Emphasis on relational autonomy. The decision partner concept constitutes a shared approach to decision-making that draws on the guidance of others—the essence of relational autonomy. The concept of relational autonomy occurs when individuals work alongside those they are in close relationships with, seeking compromises that are good for 'us' rather than weighing up competing interests (Skyrme, 2016). When considered as an individualized quality that is disassociated from relational contexts, autonomy fails to account for joint decision-making (Carnevale, 2012). Hence, the decision partner concept places emphasis on relational autonomy because it recognizes the importance of social circumstances and significant relationships on individuals' self-determination (Bell & Balneaves, 2015; Beauchamp and Childress, 2012; Sherwin, 1998).

4.6.1.1.9. Loss of privacy for patients. A possible consequence with the concept is the issue of maintaining patient privacy (Laidsaar-Powell et al., 2016c) and recognizing patient feelings of discomfort about involving others in decision-making and sharing personal medical information. When given access to private health-related information, decision partners become co-owners of someone else's information (Bute et al., 2015). There is a current emphasis on patient privacy and confidentiality, which may make decision partner roles more challenging.

4.6.1.1.10. Potential that decision partner is not well-informed about the decision that must be made. Decision partners may not always be well-informed about the healthcare decision that must be made. When this happens, it can affect the patient's decisions and diminish the decision partner's contributions to decision-making.

4.7. Empirical referents

The final step in the concept analysis is the identification of the empirical referents. These are classes or categories of actual

phenomena which, by their existence or presence, demonstrate the occurrence of the concept itself (Wahlín, 2017). Empirical referents provide specific measurable examples to verify the presence and subsistence of the concept (Walker and Avant, 1995). To date, we have not been able to identify any empirical referents for measuring the effect, existence, or attributes of the decision partner concept. However, it might be useful to consider the empirical measures related to surrogate/proxy/substitute decision-makers, as they share similar attributes to decision partners. Empirical measures for this related role include Decisional Fatigue Scale, a unidimensional measure to capture the influence of emotional distress, cognitive processing (mental exhaustion), and impulsive decision making (behaviors) (Hickman et al., 2018); Family Decision-Making Self-Efficacy Scale to evaluate family members' confidence in surrogate decision-making (Nolan et al., 2009; Green et al., 2018); Surrogate Decision Making Self-Efficacy Scale to assess self-efficacy for surrogate decision making (Lopez and Guarino, 2013); QUAL-E (Fam) to measure the quality of family experience in palliative care (Steinhauser et al., 2014); and Decisional Conflict Scale, which evaluates factors contributing to uncertainty in decision making (O'Connor, 1995).

5. Discussion

Applying the decision partner concept emphasizes often-recognized contributions to healthcare decision-making. Decision partners can serve as potential sources of support or conflict in the decision-making process. In addition to potentially influencing healthcare decisions, decision partners have the potential to recognize and acknowledge, through intimate knowledge of the patient, choices that are most patient-centered and inclusive of the patient's preferences and goals.

There are key recommendations for use and application of the decision partner concept in shaping research, practice, and policy. First, a new culture of empirical research should examine decision partners, their roles, needs, and contributions to patient health outcomes, such as quality of life, healthcare utilization, treatment costs, effectiveness of care, satisfaction with care, medical errors, readmission rates, timeliness of care, transitions of care, and mortality rates. These outcomes could be examined for differences when decision partners are engaged in decision-making compared to when they are absent. Also, how the decision partner role is impacted when combined with other roles such as the caregiver role. It is also important to examine through longitudinal studies how decision partner engagement differs as well as how engagement changes over time. More descriptive studies are needed to describe and measure the role of decision partners in different healthcare contexts and disease processes. Additionally, future research should include development of measures for decision partners to better understand, assess, and evaluate their role in triadic relationships between patients, decision partners, and healthcare professionals. Psychometric evaluations and observational studies can help assess which patient characteristics predict or warrant the need for a decision partner. There is a need to identify or develop empirical referents for measuring the effects, existence, or attributes of the decision partner concept. Furthermore, qualitative study designs may be used to explore reasons why some patients have a decision partner while others do not, as well as to understand the influence of decision partners on healthcare decision-making. Future family communication interventions could explore ways to support patient and decision partner communications surrounding shared illness experiences and decision-making. There is also a dearth of information related to how the decision partner role varies across different races and ethnicities, cultures, and geographic regions of the world. Finally, decision partners need clinician support to be well-integrated into health-related conversations, healthcare

systems, community programs, policy reform, and public health initiatives related to healthcare decision-making.

Nurses are central to healthcare, working closely with patients, their support networks, and communities. This positions nurses well to acknowledge, advocate for, and involve decision partners in healthcare decision-making while maintaining patient access to the care team. Nurses can take an active role in policy and leadership not only in healthcare but in social policy that covers the gamut of human concerns (Grady & Hinshaw, 2017). Nurses and other clinicians should be equipped to identify and understand decision partner roles, particularly as their engagement requires a shift in the traditional culture of healthcare and shared decision-making between patients and providers.

6. Conclusions

Further research on decision partners is needed to develop and assess sustainable interventions to improve healthcare decision-making for patients and families. Decision partner dimensions should also be explored, describing potential impact on decision outcomes and subsequent health outcomes as well as policy implications. In this concept analysis, we aimed to clearly define and describe the decision partner role and their potential contributions healthcare decision-making.

Contributions

Conception and design: TG; Drafting of the article or revising it critically for important intellectual content: TG, MC, JW, MN; Final approval of the version to be submitted: TG, MC, JW, MN

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Conflict of Interest

None.

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