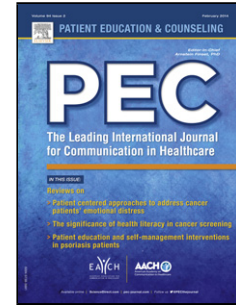


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Title:

The TRIO Framework: Conceptual insights into family caregiver involvement and influence throughout cancer treatment decision-making

Authors:

Rebekah Laidsaar-Powell¹, Phyllis Butow¹, Cathy Charles², Amiram Gafni², Vikki Entwistle³, Ronald Epstein⁴, & Ilona Juraskova¹

¹ Centre for Medical Psychology and Evidence-based Decision-making (CeMPED), School of Psychology, The University of Sydney, New South Wales, Australia

² Department of Clinical Epidemiology and Biostatistics and Centre for Health and Policy Analysis (CHEPA), McMaster University, Hamilton, Ontario, Canada

³ Health Services Research Unit, University of Aberdeen, Aberdeen, Scotland

⁴ Department of Family Medicine, University of Rochester Medical Center, Rochester, New York, USA

Corresponding author at:

Rebekah Laidsaar-Powell

School of Psychology

PoCoG, Level 6, Chris O'Brien Lifehouse (C39Z)

The University of Sydney

NSW 2006 Australia

Ph: +61 2 9036 5289

Fax: +61 2 9036 5223

Email: rebekah.laidsaar-powell@sydney.edu.au

Dedication:

This paper is dedicated to the memory of our colleague, the late Professor Cathy Charles, who made a major contribution to the TRIO conceptual framework.

Highlights

- Empirically-grounded conceptual Framework of DM with a corresponding graphical aid
- Focuses on the form and extent of family caregiver involvement in/influence over DM
- Presents six conceptual insights derived from empirical evidence and DM theory
- May serve as a useful guide for future empirical, ethical and/or theoretical work

Abstract

Objective: Family caregivers are regularly involved in cancer consultations and treatment decision-making (DM). Yet there is limited conceptual description of caregiver influence/involvement in DM. To address this, an empirically-grounded conceptual framework of triadic DM (TRIO Framework) and corresponding graphical aid (TRIO Triangle) were developed.

Methods: Jabareen's model for conceptual framework development informed multiple phases of development/validation, incorporation of empirical research and theory, and iterative revisions by an expert advisory group.

Results: Findings coalesced into six empirically-grounded conceptual insights: i) Caregiver influence over a decision is variable *amongst* different groups; ii) Caregiver influence is variable *within* the one triad *over time*; iii) Caregivers are *involved* in various ways in the wider DM process; iv) DM is *not only amongst three*, but can occur among wider social networks; v) Many *factors* may affect the form and extent of caregiver involvement in DM; vi) Caregiver influence over, and involvement in, DM is linked to their *everyday involvement in illness care/management*.

Conclusion: The TRIO Framework/Triangle may serve as a useful guide for future empirical, ethical and/or theoretical work.

Practice Implications: This Framework can deepen clinicians's and researcher's understanding of the diverse and varying scope of caregiver involvement and influence in DM.

Keywords:

family caregivers; triadic; medical decision-making; conceptual framework;

1. Introduction

Family caregivers regularly attend cancer consultations with an adult patient (accompaniment rates range from 64-86%) [1, 2]. Typically one *key family* caregiver attends, and this is usually the patient's spouse/partner or adult child (less commonly a patient's parent, sibling, other relative or friend) **who is involved in the care of the patient** [3]. This *key* family caregiver also often participates in the decision-making (DM) process [4]- some in a supportive or facilitative capacity, while others are involved more directly in DM.

The involvement of **family** caregivers in DM may be particularly important among some families, as medical decisions often impact not only the patient, but also the **family** caregiver [5, 6]. For example, the spouse of a young adult patient is likely to be directly impacted by a decision to undergo treatment which affects fertility. Correspondingly, daily life will be affected for the adult child caregiver of an elderly patient who decides to receive daily outpatient treatment requiring transportation and accompaniment to the hospital. Finally, family caregivers will be impacted by a decision for the patient to receive home-based palliative care and die at home. Despite the frequent involvement of family caregivers in consultations and decisions, most *conceptual* papers discussing medical DM published to date have focused on the clinician-patient dyad [see 7] rather than the clinician-patient-family caregiver triad and larger social networks. However, a growing *empirical* literature acknowledges the significant role of **family** caregivers in medical DM.

Most cancer patients (49-84%) and **family** caregivers (54-59%) report both preferring and experiencing some family caregiver involvement in DM [8-12]. However the form and extent of family involvement in DM appears to vary widely. Most patients and **family** caregivers prefer family caregivers' involvement to be facilitative or collaborative [9, 12], and this preference is reflected in practice. In a US study examining the experiences of over 5,000 patients with lung and colorectal cancer, 1.5% of the sample reported their family made important decisions on their behalf, 49.4% reported equally sharing decisions with family, 22.1% reported some family involvement, and 28.5% of patients reported little or no role for their family in DM. Interaction analyses of audio/video-taped medical consultations similarly highlight that **family** caregivers are often actively involved in consultation communication [e.g. 2, 13], and DM [13-15]; and also reveal that **family** caregiver involvement in DM is variable both across consultations and among different triads [13]. **Family** caregiver involvement in DM can vary on a spectrum from passive to dominant

[4, 16, 17] and the form/extent of involvement may be influenced by contextual factors such as the patient's age, gender, health status, cultural background and relationship with the **family** caregiver [11, 18]. Despite the growing empirical evidence base, there remains limited conceptual description of **family** caregiver involvement in DM.

1.1 Conceptual frameworks of family caregiver involvement in DM

Whilst the majority of conceptual publications to date have focused on the clinician-patient dyad, some more recent publications have started to acknowledge the importance of significant others, including family caregivers. For example, Rapley's [19] account of 'distributed DM' highlights that decisions are embedded within and are shaped by social interactions, which can include family and friends within and outside the medical consultation. Additionally, Epstein and Street's [20] concept of 'shared mind' proposes that decisions may be made within social networks, where new ideas and perspectives may emerge through the sharing of thoughts and feelings between individuals (including family and friends of a patient). Elwyn et al.'s [21] model of collaborative deliberation similarly acknowledges that DM is not usually done in isolation and recognises the value of collaboration between individuals (including clinicians, family, and friends). Additionally, Légaré et al.'s [22] Interprofessional Shared DM model (IP-SDM) explains that many members of the inter-professional team as well as family caregivers are involved in the treatment DM process. Whilst these conceptual publications of medical DM have started to *acknowledge* the input of **family** caregivers in DM, clear delineation of family caregiver roles and dynamics within the DM process remain largely unexplained.

A limited number of more specific conceptual descriptions of **family** caregiver involvement in DM have also been published. These conceptual descriptions have predominantly been typologies based on qualitative data, which describe how **family** caregiver involvement in the DM process varies along a spectrum from passive to dominant [16, 17, 23, 24]. Two triadic process models have also been proposed [25, 26], which posit how triadic interactions and patient outcomes (e.g. satisfaction, knowledge, and adherence) are influenced by factors including patient/family/clinician personality, knowledge, and attitudes. However, these existing descriptions do not capture the complex interactions and dynamics of all three participants (physician-patient-**family** caregiver) in the DM process.

1.2 The issues with 'ideal' or 'gold standard' DM styles when caregivers are involved

Besides Krieger [27], who proposed that aligned patient-**family** caregiver preferences for the extent of caregiver involvement in DM are preferable, there has been little prescription of 'ideal' or

'gold standard' forms or levels of **family** caregiver involvement in DM. Various ethical discussion papers have, however, proposed that there are preferred forms/levels of **family** caregiver involvement in DM; some advocating that individual patient autonomy should be maintained, with **family** caregivers assuming a supporting role [e.g. 28, 29], while others have suggested that **family** caregivers deserve to have an influential role in the DM process [5, 6, 30, 31], as they are often affected by the decision. Given the different ethical perspectives, and the fact that patient and **family** caregiver preferences vary widely, it is unlikely that there is a single '*ideal*' or '*gold standard*' model of **family** caregiver involvement in DM. However, delineation of the range of options in triadic DM may assist future discourse about which forms or levels of family caregiver involvement might be more appropriate, and why, in particular situations. **Furthermore, a flexible model that fits with what both the patient and family caregiver need, value and want - with consideration of the clinical scenario and input from the clinician - could be considered 'ideal.'**

1.3 Aims

To address persistent gaps in the conceptual literature, this paper proposes an empirically grounded framework of DM **involving TRIadic Interactions in Oncology** (TRIO Framework), which specifically aims to: i) depict the accommodation of **family** caregivers into the existing conceptualisation of clinician-patient DM; ii) explore the possible range of family caregiver influence over medical decisions and iii) describe the complexity and variability of **family** caregiver involvement in DM.

1.3.1 Scope and purpose of the TRIO Framework

The TRIO Framework focuses on the common scenario of one cognitively competent adult cancer patient, one *key* clinician (usually, but not restricted to, an oncology physician), and one *key* adult family caregiver (a person related to the patient biologically, legally, or emotionally, usually accompanying the patient to medical consultations **and assisting in the patient's care**). The purpose of the TRIO Framework is to help characterise the involvement of family caregivers, and purposefully does not propose any ideal or preferred style of **family** caregiver involvement in DM. This Framework was developed based on cancer treatment DM, but is likely generalisable to other similar medical contexts.

2. Methods

2.1 Conceptual framework development

In this paper, a conceptual framework is defined as “a network, or a plane, of interlinked concepts that together provide a comprehensive understanding of a phenomenon” [32]. While the TRIO Framework development process was iterative and flexible in nature, it largely followed the eight main phases of conceptual framework development outlined by Jabareen [32].

2.1.1 Phases 1-2: *Mapping the selected data sources* (Phase 1) was achieved through conducting a systematic review of empirical studies examining clinician-patient-family caregiver communication and DM [33] as well as reviewing relevant conceptual, ethical, and legal perspectives on **family** caregiver involvement in DM [34]. Relevant data from qualitative interviews with oncology clinicians, patients, and family caregivers [4] and interaction analyses of triadic consultation audiotapes [13], were also appraised. *Extensive reading and categorizing of the selected data* (Phase 2) involved examining literature for relevant information to be included in the Framework.

2.1.2 Phases 3- 6: *Identifying and naming concepts* (Phase 3) emerging from the literature and flexibly *deconstructing, categorising* (Phase 4) and then *integrating* (Phase 5) concepts with similarities to develop new overarching concepts was conducted. Phase 6 involved the *synthesis* of concepts into a theoretical framework. As highlighted by Jabareen [32] this phase is “*iterative and includes repetitive synthesis and resynthesis until the researcher recognizes a general theoretical framework that makes sense*”. Phases 2-6 were initially conducted by RL-P, PB, and IJ during a 3-day intensive workshop. A draft Framework was then sent to CC, AG, VE, and RE, who provided written feedback and engaged in teleconference discussions. The TRIO Framework underwent several subsequent iterations, with all co-authors providing written feedback and engaging in teleconference/email discussions for each draft.

2.1.3 Phase 7: *Validating the conceptual framework* was achieved using multiple methods. The Framework was applied to: i) empirical examples of **family** caregiver involvement in DM derived from interviews with health professionals, patients, and **family** caregivers [4] and ii) audiotaped oncology consultations [13] to test its scope to accommodate a variety of triadic DM styles and behaviours. As recommended by Jabareen [32], the TRIO Framework was presented at relevant conferences (International Shared Decision-Making Conference, Sydney, Australia, 2015; European Association of Communication in Healthcare Conference, Heidelberg, Germany, 2016; Clinical Oncology Society of Australia, Hobart, Australia, 2015) to test its acceptability and usefulness among researchers and clinicians. Feedback was incorporated into the TRIO Framework. The acceptability of the corresponding graphical aid (the TRIO Triangle), and its validity in conveying

triadic dynamics, was tested and established in a study among undergraduate psychology students [35].

2.1.4 Phase 8: *Development of the conceptual framework* remains ongoing as “a theoretical framework representing a multidisciplinary phenomenon will always be dynamic and may be revised according to new insights, comments, and literature” [32].

3. Results

3.1 The TRIO Framework

At the core of the TRIO Framework are six important conceptual insights (Concepts) derived from our program of empirical research and the wider evidence base. They include:

- Concept 1: **Family** caregiver influence over a decision is variable *amongst* different groups
- Concept 2: **Family** caregiver influence is variable *within* the one triad *over time*
- Concept 3: **Family** caregivers are *involved* in various ways in the wider DM process
- Concept 4: DM is *not only amongst three*, but can occur among wider social networks
- Concept 5: Many *factors* may affect the form and extent of **family** caregiver involvement in DM
- Concept 6: Family caregiver influence over, and involvement in, DM is linked to their *everyday involvement in illness care and management*

The empirically-derived conceptual insights, which underpin the TRIO Framework, will be further described throughout this paper, with some being graphically conveyed using a triangle (the TRIO Triangle) to aid readers’ understanding. A triangle (see Figure 1) was chosen as it accommodated the triadic nature of DM between the patient, *key* clinician, and *key* family caregiver. Triangles have previously been used to convey the clinician-patient-family relationship [see 36]. The TRIO Triangle should be considered as a tool to understanding some aspects of the wider and more comprehensive TRIO Framework.

3.2 Family caregiver Influence: Development of the TRIO Triangle

Within the clinician-patient dyad, influence over a medical decision is often presented as varying along a spectrum, ranging from ‘paternalism’ (clinician-led DM) to the ‘informed’ approach (patient-led DM). Shared DM between the clinician and patient has commonly been placed in the ‘middle’ of these two ‘anchor points’ [e.g. 37]. However it is clear that a **family** caregiver could not fit along this unidimensional line. Our [4, 13] and others’ [e.g. 4, 13, 16, 17] empirical work points

to the fact that, in many cases, a **family** caregiver is influential in the DM process, and their influence over a decision can similarly rest on a spectrum from passive, to shared, to dominant.

Based on this we propose that, instead of a unidimensional line (see Figure 1, Section 1), a triangle is a more appropriate starting point to capture and express the complex scope of clinician-patient-**family** caregiver influence over a decision (see Figure 1, Section 2). It is proposed that each of the three points of the triangle represent the *dominant influence* of a specific individual during a DM interaction (e.g. clinician-led DM; patient-led DM; or **family** caregiver-led DM).

The TRIO Triangle also depicts the dyadic *sharing* of influence over a decision between two parties at the midpoint between two points of the triangle (i.e. shared clinician-patient DM; shared clinician-**family** caregiver DM; shared patient-**family** caregiver DM). The triadic ‘equal’ *sharing* of a decision between all three parties is located at the very centre of the triangle space (i.e. triadic DM between the patient, *key* clinician, and *key* family member) (see Figure 1, Section 3). The positioning of the clinician at the apex of the triangle was purposeful, given that they typically hold dual roles within triadic DM, namely: i) as a *participant* within the DM process and ii) as the *facilitator* of triadic DM discussions within consultations, having the medical expertise and a professional role in the DM process.

An important point raised by Charles et al. [37] was that, in reality, clinician-patient DM does not exist only in these ‘*pure*’ or ‘*extreme*’ approaches (i.e. paternalistic approach, shared approach, informed approach). Rather, a multitude of intermediate/hybrid approaches exist along the unidimensional line. Similarly, we propose that real clinician-patient-**family** caregiver influence over a decision is likely to rest somewhere *within the triangle space* as an intermediate/hybrid approach existing within a *spectrum* (see Figure 1, Section 4), **versus the 7 “pure” approaches depicted by the points and mid-points of the triangle.**

3.3 A comment on influence vs. involvement

The TRIO Triangle and Concepts 1 (**family** caregiver influence over a decision is variable amongst different groups) and 2 (**family** caregiver influence is variable within the one triad over time) discuss and depict the notion of **family** caregiver ‘*influence*’, that is, lead contributions to the shaping of the medical decision. *Influence* is conceptualized in the Triangle as being relative, where the more *influence* one party has- the less *influence* the others can have over a decision. There can,

however, be points of equilibrium and sharing of influence, which are denoted in the TRIO Triangle as shared dyadic and shared triadic DM.

Whilst family caregiver *influence* is the primary focus of the TRIO Triangle and Concepts 1 and 2, in other elements of the Framework we acknowledge (and where possible comment on) the wider concept of family *involvement* in the DM process. *Involvement* in DM can manifest in varied ways, including the more obvious/concrete family caregiver *involvement* in information exchange (e.g. researching treatments, providing information, questioning options) and deliberation (e.g. providing an opinion, explicitly stating support of patient preferences), but also in more subtle/abstract ways as proposed by Entwistle and Watt [38], such as a ‘*sense of being a part of*’ a decision, a ‘*commitment to being there for*’ the patient during DM, or ‘*being significantly impacted by*’ the decision. The broader concept of family caregiver *involvement* will be discussed in Concepts 3-6.

[INSERT FIGURE 1 HERE]

The six empirically-grounded conceptual insights (Concepts) that form the core of the TRIO Framework will now be outlined in detail.

3.4 Concept 1: Family caregiver influence over a decision is variable amongst different groups

An important empirical finding within the evidence base [4, 13, 16, 17] was the variability of **family** caregiver influence *among* triads. For example, in some cases the **family** caregiver was very passive and did not influence the decision whilst the patient and clinician shared the decision; in other triads, the **family** caregiver assumed a dominant role in DM while the patient and clinician had limited input.

“So there are times when patients will actually say, “Look, just ask him”, or, “Ask her, I just don’t feel like I can make another decision”. So it really depends where they’re at---“ Nurse [4].

Figure 2 provides case examples of three different triadic dynamics, to illustrate this variability *amongst* triads.

[INSERT FIGURE 2 HERE]

3.5 Concept 2: Family caregiver influence is variable within the one triad over time

In addition to *among*-triad variability, existing empirical literature points to the dynamism of **family** caregiver involvement *within* the one triad *over time*. For example, patients in our qualitative study reported that their **family** caregiver’s *influence* over decisions evolved throughout

the illness trajectory, where sometimes caregivers were required to take a more influential role in the DM process, and at other times they assumed a more passive role, as the patient's needs and abilities fluctuated over time [4], thus, **the role of a family member:**

“will vary in the situation and it might vary even at different consultations. ... It's a moveable dynamic”. [4]

To highlight the changing nature of **family** caregiver influence over decisions within the one triad, a case example is provided in Figure 3, where points A, B, C, D, and E represent different decision points within one patient's illness trajectory.

[INSERT FIGURE 3 HERE]

3.6 Concept 3: Family caregivers are involved, in various ways, in the wider DM process

As highlighted in Concepts 1 and 2, family caregivers may exert *influence* over the decision to be implemented, and this level of influence may differ amongst different triads and within the one triad over time. In addition, our research has found that family are commonly *involved* in the DM process in many ways across the various stages of DM [4]. **See Table 1 for supporting quotes. For example, family** caregivers may be involved in: i) *pre consultation preparation* (e.g. researching which doctor to see, reading results of scans, preempting treatment options and discussing these with the patient); ii) *information exchange* (e.g. gathering/contributing information about treatments; asking questions; recalling information; providing medical information about the patient; providing social information about the patient/ themselves; questioning information provided by the clinician); and iii) *deliberation* (e.g. acting as a 'sounding board'; supporting and advocating for the patient's wishes; undermining the patient's preferences; providing own opinions/preferences). It is through these behaviours/actions that family caregivers often exert *influence* over a decision, which can be perceived as positive, negative, or neutral contributions to the DM process. In addition, some of these family caregiver actions may also achieve other outcomes such as providing the patient with comfort and support, enhancing (or undermining) the patient's autonomy, and/or reassuring the clinician that the patient has had adequate support when making a decision.

Table 1 about here

3.7 Concept 4: DM is not only amongst three

One patient, one *key* clinician, and one *key* family caregiver were the most commonly reported participants involved in consultations and DM discussions in our series of qualitative studies [3, 4, 39]. However, the wider ‘social networks’ of each of these key stakeholders may also be *involved* in the DM process and influential over the final decision, including other patients, family members, health professionals, friends, and neighbours [17, 40]. In addition, a growing body of evidence is recognising that clinicians also exist within interprofessional networks, and other clinicians, allied health team members, and healthcare administrators may inform the clinician’s position within the DM process [41-43]. Indeed, the *involvement* of other health professionals is well documented in situations where complex medical decisions are discussed at multidisciplinary team meetings [e.g. 44].

These findings align with Epstein and Street’s [20] concept of ‘shared mind’ decision processes, particularly the notion that decisions are made within social networks. Recognising that patients often discuss decisions with trusted family, friends, and clinicians before and after consultations, Epstein [45] proposed that it is important to recognise these complex social networks and how they can affect DM, as their *involvement* and *influence* may not be outwardly apparent, particularly in the consultation environment.

Figure 4 depicts a sociogram, a simplified version of a *social network analysis* which depicts hypothetical interrelationships among networks of key individuals [46]. More specifically, it highlights that, while there is usually a core ‘triad’ of individuals involved in a decision, many other individuals may exist within a wider social network. In Figure 4, the patient and **family** caregiver networks are purposefully intertwined, as it is likely they will share a number of influential family members and friends.

[INSERT FIGURE 4 HERE]

3.8 Concept 5: Many factors may affect the form and extent of family caregiver involvement in DM

A number of factors (e.g. demographic, psychological, relational, cultural, and medical) may impact on the type of involvement **family** caregivers assume and the level of influence they have over a decision. **See Table 2 for supporting quotes from our qualitative study [4].**

The demographic characteristics of patients and **family** caregivers (e.g. age, gender, education level, **health literacy** [[47] may have an impact on caregiver involvement. For example, **one study noted that** family caregivers are more likely to be actively involved in DM when patients were

older or female, **perhaps due to gender roles** [18]. Oncology clinicians in our groups' qualitative study also proposed that **family** caregivers may assume a greater role in DM when the patient was younger or older (rather than middle aged) and/or had a lower level of education while more actively involved caregivers tend to be middle aged, female, and well-educated [4].

Psychological characteristics of participants, such as their mental health, coping, and personality traits may also impact upon the extent of **family** caregiver involvement. For example, Street and Gordon [2] found a non-significant trend for **family** caregivers of patients reporting better mental health to be less active in the consultation, and in our work [4], oncology clinicians reported that for patients with mental illness such as depression or anxiety, or with 'withdrawn' personalities, **family** caregivers had greater involvement and influence over decisions. **These oncology clinicians posited that such psychological characteristics increased patient vulnerability, and made it more difficult for them to self-advocate or speak up in consultations. Other literature suggests that psychological empowerment correlated with older adults' preferred and perceived involvement in medical decision-making** [47].

The history and general nature of the relationship between participants, particularly between the patient and **family** caregiver, may also impact on the level of caregiver involvement and their subsequent influence. For example, **family** caregiver involvement in DM is increased among married/de-facto patient-caregiver pairs compared to other caregivers [11, 18], and when caregivers report a close and strong relationship with the patient [4].

Cultural and societal factors, such as cultural norms or language ability, may also impact on the extent that **family** caregiver input is desired and considered appropriate. For example, it has been found that families were typically more involved and influential if the patient was of Chinese decent [18] or if the caregiver or patient was a migrant from a non-English speaking country [4]. **Social support provided to the family caregiver by others in the wider circle may also influence caregiver capacity to be involved in decision-making** [48].

The nature and severity of the disease may also influence **family** caregiver involvement. **Family** caregivers are more likely to be involved in DM for patients with more severe/advanced illnesses (e.g. advanced cancer) compared to milder or more short-term illnesses/injuries (e.g. ear infection) [11, 49].

Finally, the nature and significance of the decision may influence the extent of **family** caregiver involvement. Oncology clinicians proposed that **family** caregivers may be more involved when the

decision is complex, significant, or when the caregiver is heavily impacted by the decision [4]. For example, for cancers in which there are more innovative / cutting edge treatments available and outcomes are still uncertain, patients may look to **family** caregivers more to support their decision-making versus for cancers with fewer treatment options [50]. Likewise, **family** caregivers may have more input into treatments such as stem cell transplant given the intense nature of this type of treatment and recovery.[51, 52]. However to our knowledge no studies have quantitatively tested this within the triadic context.

Table 2 about here

3.9 Concept 6: Family caregiver influence over, and involvement in, DM is linked to their everyday involvement in illness care and management

Empirical work by our group in Australia [4] highlights that **family** caregivers can assume a range of roles within and beyond the medical consultation (e.g. provision of emotional support, assistance with information, transportation, medication management, home-based medical care, assistance with activities of daily living, financial support). These, and the many other roles, which **family** caregivers may assume throughout a patient's illness, may foster and be examples of the more subtle types of *involvement* in a decision, as proposed by Entwistle and Watt [38], which may be considered as valuable contributions to patient care in their own right, as well as potentially influencing the DM process in an indirect manner.

4. Discussion and conclusion

4.1 Discussion

The TRIO Framework provides the first comprehensive description of **family** caregiver involvement in, and influence over, cancer treatment decisions. It has been rigorously developed, informed by our own program of research [4, 13, 33]; as well as a comprehensive review of other relevant empirical, conceptual, ethical, and legal publications, and iterative feedback from an advisory group of experts in ethics, medical oncology, psychology, and theory development. These strong empirical foundations underpinning the TRIO Framework enhance the validity and clinical relevance of the TRIO Framework, with several empirical examples derived from our interview [4] and consultation transcript [13] studies used to test the Framework's effectiveness in depicting the real behaviours and dynamics occurring during triadic DM.

A key strength of the TRIO Framework is that the focus on family caregivers is explored in the wider context of the clinician-patient-**family** caregiver triad. Through use of conceptual insights and graphical aids (TRIO Triangle), the TRIO Framework is able to describe some of the complex interactions and dynamics of all three core participants (patient, *key* clinician, *key* family caregiver) in the triadic DM process. More specifically, the TRIO Framework describes a number of empirically-grounded conceptual insights relating to **family** caregiver influence and involvement in the DM process, such as the variability of caregiver influence within and among groups, the wider social networks (beyond the triad) involved and invested in the DM process, the array of contextual factors which may affect the extent of caregiver involvement in DM, and the interrelationship between caregivers' roles in everyday illness management and DM.

The TRIO Framework has purposefully examined both the narrower concept of **family** caregiver *influence* over a decision, as well as the broader concept of **family** caregiver *involvement* in the DM process, including information exchange, deliberation and making the actual decision. These concepts were purposefully teased apart to highlight the many roles and impacts family caregivers have when involved in DM. In some cases, **family** caregiver *involvement* in DM is clearly linked to their level of *influence* over the final decision. For example, the wife of a prostate cancer patient researches which cancer treatment centre her husband should attend, provides him with information about the cancer and potential treatments, actively engages in the consultation discussions, and clearly articulates her preferences for a particular course of treatment, while the patient listens to his wife, takes into account all of her recommendations, and decides to receive the treatment she advocates. However, in many cases, **family** caregivers may be heavily *involved* in the DM process, but have limited *influence* over the final treatment to be implemented. For example, the adult son of a breast cancer patient researches and provides information about treatment options, attends consultations, acts as a sounding board when the patient is deliberating over the decision, and helps arrange the logistical aspects of her treatment, while the patient strongly believes it is "*her body, her decision*" and makes the decision for treatment independent of her son's preferences. This approach to **family** caregiver involvement in DM was commonly discussed by participants in our groups' qualitative study [4], with one family caregiver stating "[Patient] pretty much made [the decision] by herself. . . I deliberately wouldn't have influenced the decision. So in a lot of ways it was "how could I make it easier for her?" or "how could I facilitate the process of her making the decision?". Therefore, it is important for researchers and clinicians to not only consider the extent of family *influence* over the decision that a patient may prefer, but also the type and amount of family *involvement* in the broader DM process.

The TRIO Framework is likely to be useful in several ways. First, it provides an empirically-based platform for depicting the scope of triadic influence in medical DM, and may be a useful guide for further research in the area. Indeed, the TRIO Triangle itself could be conceptualised as a map to help understand the complex landscape of the **family** caregiver's relative influence over a decision. For example, it may form the basis of ethical, legal, and clinical discussions debating whether some areas of the triangle are preferable in certain contexts (e.g. for patients with dementia, adolescent patients, fertility treatment DM) and when approaches taken by any member of the triad conflicts with that taken by another member, such as an assertive patient encountering a paternalistic physician or a caring but misguided **family** caregiver tries to direct a patient's choice.

In addition, by depicting a spectrum of **family** caregiver influence in DM, the TRIO Framework could be used to educate health professionals about the diverse and varying scope of **family** caregiver involvement and influence. This Framework also highlights that, in reality, there are many intermediate and nuanced styles that lie between the seven 'pure' styles. The identification of intermediate styles increases options for clinicians when they are discussing **family** caregiver involvement with patients (and potentially caregivers). Additionally, the point that DM styles may vary across an illness experience reinforces the importance of flexibility so that clinicians are able to recognise and respond to the evolving preferences and behaviours of patients and **family** caregivers over time. The identification of influencing factors also highlights that one factor (e.g. patient age or culture) is unlikely to solely influence the extent of **family** caregiver involvement; rather a complex web of factors are likely to influence DM styles. Clinicians should thus avoid assumptions based on a single characteristic of the patient or caregiver (e.g. all wives want to be heavily involved in DM). With further research and validation, a simplified form of the triangle could be useful in obtaining patient and/or **family** caregiver preferences for triadic DM dynamics.

As highlighted in Concept 6, a **family** caregiver's involvement in DM may be underpinned by their broader participation in the everyday care and management of the patient's illness, such as emotional support, practical/logistical support, and home-based medical care. Indeed, many of the conceptual insights in the TRIO Framework, such as Concept 1 (**family** caregiver influence over a decision is variable *among* groups), Concept 2 (**family** caregiver influence is variable *within* the one triad *over time*), and Concept 5 (many *factors* may affect the form and extent of **family** caregiver involvement in DM) apply not only to the narrower concept of treatment DM, but to many aspects of the much broader concept of illness care and management. For example, the amount and type of home-based medical care a family caregiver provides is likely to vary throughout the course of an

illness (e.g. more active caregiver involvement during flare-ups) and is likely to be influenced by a number of contextual factors (e.g. the nature/closeness of the patient-**family** caregiver relationship, cultural expectations about caregiver roles).

Whilst the TRIO Framework focuses on **family** caregiver involvement when a patient is cognitively competent, many of the conceptual insights may also apply in situations where a patient has impaired cognitive capacity (e.g. early stage dementia, mild intellectual disability). Cognitive capacity should not be thought of as a dichotomous construct, but rather a more complex construct existing along a continuum from low to high cognitive ability, varying depending on the complexity of the decision, and able to fluctuate over time [e.g. 53]. Indeed, it has been argued that seriously ill (but legally cognitively competent) patients are also often cognitively compromised in subtle ways-facing a potentially terminal illness can result in cognitive biases and difficulty assimilating complex information. The facilitative and supportive behaviours of **family** caregivers discussed in Concept 4 (e.g. within a consultation asking questions, recalling medical information, providing information about the patient, acting as a 'sounding board', advocating for the patient's wishes) and Concept 6 (e.g. providing emotional support, transportation, medication management, home-based medical care, financial support) may be particularly vital in situations where patients have impaired DM abilities, to encourage and enhance enactment of the patient's wishes. A model of 'supported decision-making', clearly outlining helpful behaviours and steps for family caregivers to enhance the autonomy of patients with cognitive impairment, may be a valuable future addition to the evidence base.

Whilst a number of exciting opportunities exist for application and extension of the TRIO Framework, further discourse and research is needed to fully understand its relevance and reach. **For example, research to validate the Framework could test its fit for a series of specific cases with varied individuals, decisions, and contexts. Interventions based on the Framework could also be evaluated to determine whether they alter placement within the TRIO triangle in ways concordant with patient, family member and clinician preferences.**

4.2 Limitations

The TRIO Framework characterizes important aspects of **family** caregiver involvement in DM, however it also has some limitations. As the TRIO Triangle focuses on the core 'triad' (patient, *key* clinician, *key* family caregiver), it would need to be expanded to adequately represent more complex situations and those involving larger social networks, such as when there are two or more

family caregivers who occupy important roles. Further development of the TRIO Framework will be needed to capture more complex relationship dynamics among the parties in the triad such as conflicts, undue family influence, and coalition formation.

4.3 Conclusion

This paper proposes the TRIO Framework, which provides an expanded representation of medical DM styles, accommodating the influence and involvement of **family** caregivers. We believe that this conceptual framework will help to guide future DM research, and also to deepen health professionals' and researchers' understanding of the array of possible triadic DM dynamics, inside and outside the consultation. Given the many (practical, theoretical, ethical, legal) complexities of triadic DM, our conceptualisation and articulation of **family** caregiver *involvement* in the DM process, and their ultimate *influence* over the decision to be implemented, is likely to continue to evolve based on emerging evidence and new perspectives.

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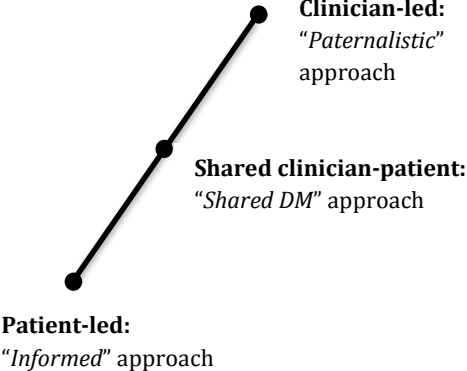
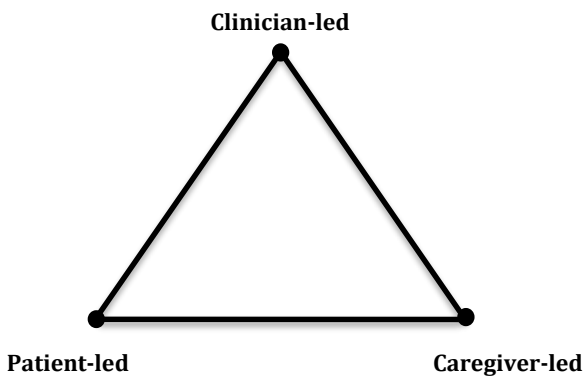
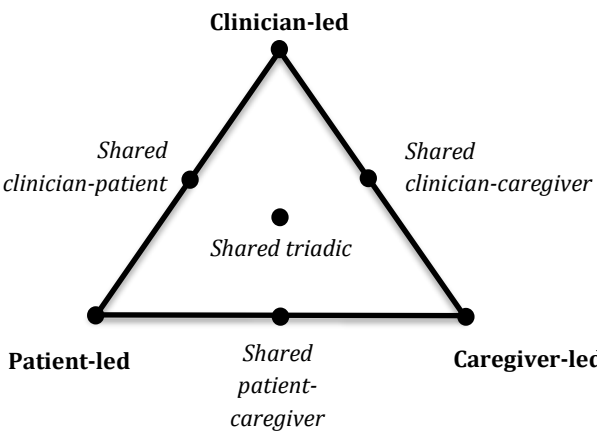
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Figure 1: Developing the TRIO Triangle

<p>5. The beginnings of a conceptual framework: Starting from the dyad</p> <p>The starting point of our graphical conceptualisation of DM was the dyadic (clinician-patient) spectral line, with clinician-led DM (paternalistic approach) at one extreme, patient-led DM (informed approach) at the other extreme and shared clinician-patient DM (shared DM approach) depicted as the black dot in the middle.</p> <p>However, our team perceived limited space for caregivers on this line, and therefore expansion was deemed necessary.</p>	
<p>6. Expanding the clinician-patient conceptualisation to include caregivers</p> <p>Our team proposes that a triangle best depicts the dynamics of the clinician, patient, and <i>key</i> family caregiver influence over a decision. In this graphical depiction, each anchor point (black dot) of the triangle represents an 'extreme' or 'pure' position, where one party has dominant influence over a decision.</p>	
<p>7. Introducing shared approaches within a triad</p> <p>Just as <i>shared</i> DM can be positioned at the midpoint of the clinician-led and patient-led approaches in dyadic DM (see section 1), so too can <i>shared</i> approaches be positioned within the midpoints of the TRIO Triangle. It is important to note that just because all three parties have the <i>potential</i> to exert influence over a decision, it does not mean that they will do so. Therefore, the three mid-line points on the TRIO Triangle represent three-types of dyadic <i>shared</i> DM that might exist when three parties are involved (clinician-patient; clinician-caregiver; or patient-caregiver).</p> <p>In addition, the midpoint in the triangle space represents the sharing of DM influence between all three parties, representing shared triadic (clinician-patient-caregiver) DM.</p> <p>However, in reality, it is unlikely that any of these 7 depicted approaches exist in their pure form. Like Charles et al. [48] proposed, DM in the <i>real world</i> will be a more complex hybrid mix of these theoretical extremes.</p>	

4. Caregiver influence as a spectrum

We propose that, in the *real world*, the dynamics of influence over a decision between a patient, *key* clinician, and *key* family member are likely to rest somewhere within the triangle space as an intermediate style. It is conceptualised that DM when a caregiver is present rests on a triadic *spectrum* which can shift from dominant influence of one individual (triangle point- e.g. clinician-led DM) to complete triadic sharing of the decision (triangle centre- shared triadic DM). The influence of a caregiver in DM may rest in *any position within this triangle space*.

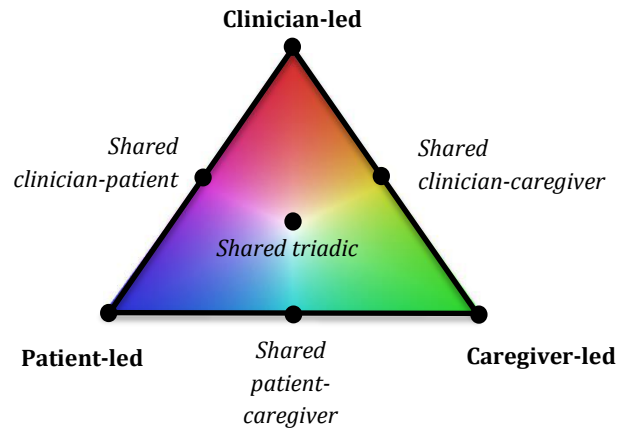
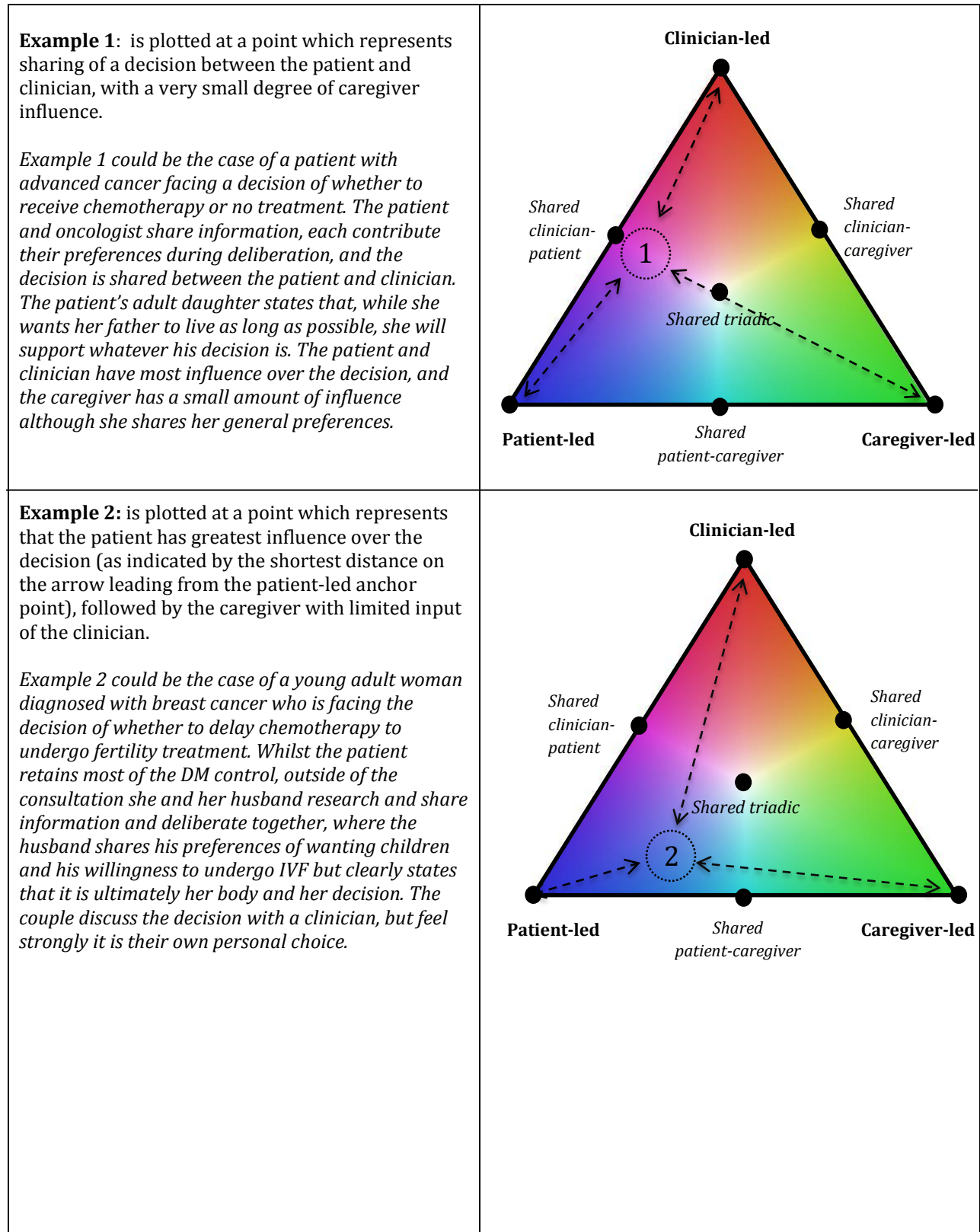


Figure 2: The variability of caregiver influence amongst different triads



Example 3: is plotted at a point which represents that the caregiver has greatest influence over the decision (as indicated by the shortest distance on the arrow leading from the caregiver-led anchor point), followed by the clinician with very limited influence of the patient.

Example 3 could be the case of a patient with limited English language proficiency who is diagnosed with lung cancer. His son (fluent in English) directs the information exchange with the clinician in all consultations and translates a small amount of the information for the patient. The son directs the deliberation process, not conveying the patient's wishes. The treatment decision is largely directed by the patient's son, to which the patient consents.

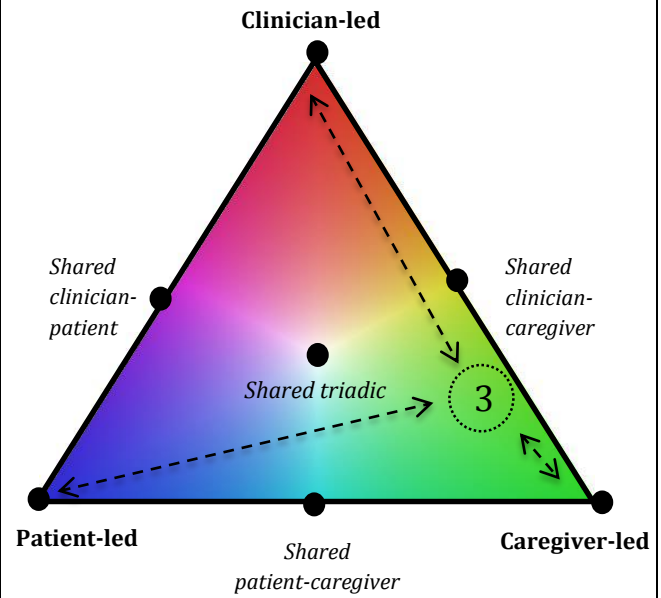


Figure 3: The variability of caregiver influence within the one triad over time

The following is a case example of the variability of caregiver influence over a number of decisions within the one illness experience.

A person suffers from a seizure and becomes unconscious at work and is brought to the emergency room where the responsible clinician orders a number of diagnostic tests and treatments on the patient's behalf **(A)**.

The patient's spouse is called and is informed that the patient has had a large brain bleed caused by a brain tumor and will require surgery. The clinician and spouse share the decision to operate immediately **(B)**.

The surgery is successful and after a period of time the patient regains consciousness. The patient is informed of their diagnosis of a brain tumor and radiotherapy is discussed and decided upon between the patient, clinician, and spouse **(C)**.

After the patient is discharged from hospital, the patient and spouse begin researching steroid therapy. They discuss this decision at length at home sharing their information, opinions and preferences. The patient and spouse make a decision together with limited input from a clinician **(D)**.

After a period of time, the patient's cancer recurs in the brain. The patient researches the implications of this recurrence, deliberates alone, and makes the decision, relatively independently of his spouse and clinician, to cease treatment **(E)**.

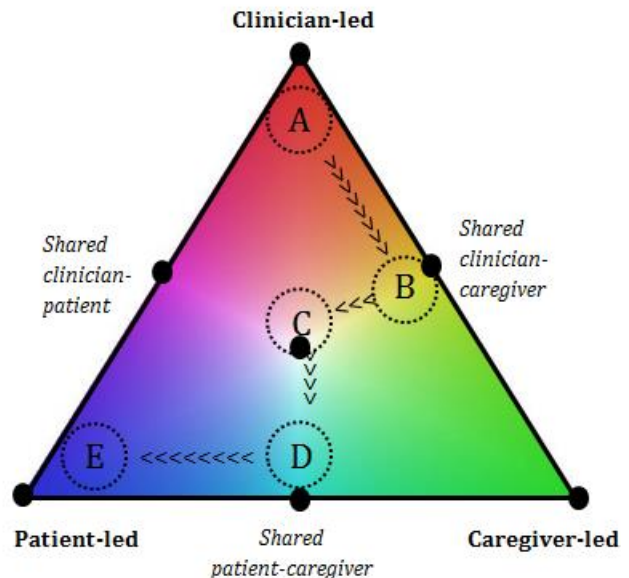


Figure 4: A hypothetical social network involved in a medical decision

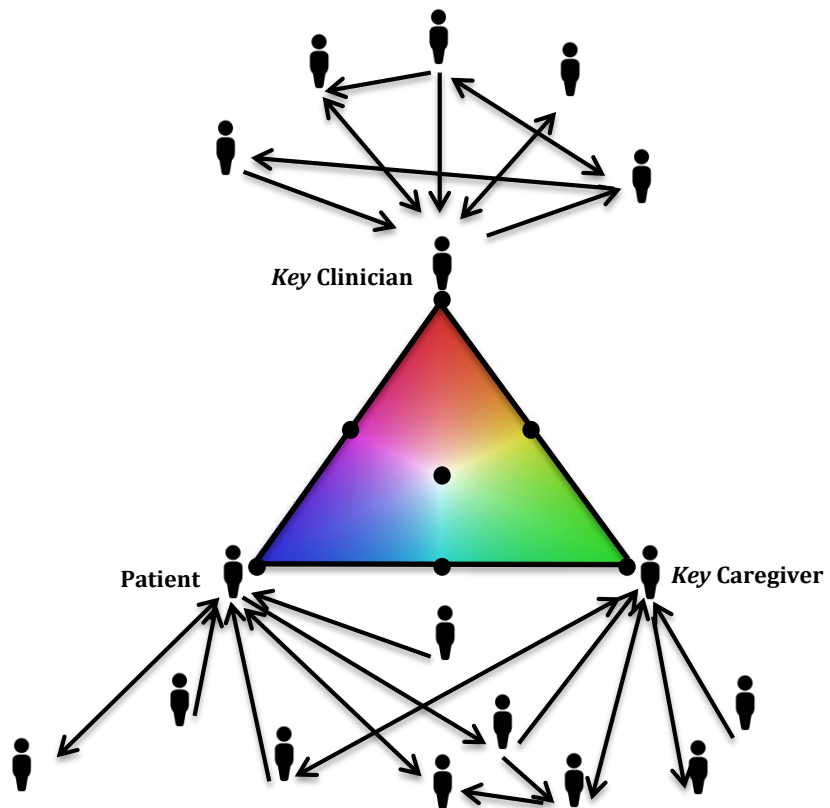


Table 1: Stages of decision-making in the triad: Illustrative quotations

Pre consultation
<ul style="list-style-type: none"> • <i>And I said look there's also this other doctor.... let's research him, so I researched him and found out that he was super duper---</i> Family member • <i>We had already made up our mind before we went in there---</i> Family member
Information exchange
<ul style="list-style-type: none"> • <i>When she was looking at alternative therapy I was a little bit concerned about what she was considering... So I researched it myself and got more information and suggested that she discuss it with the oncologist---</i> Family member
Deliberation
<ul style="list-style-type: none"> • <i>Where it wasn't a clear cut path I think that it's sort of been a dialogue and... sort of a Socratic (method) in a way that it goes back and forth and back and forth and eventually...the pathway does sort of emerge---</i> Patient
Decision
<ul style="list-style-type: none"> • <i>I think in about 90% of situations, it will be the patient who verbally says, "I will do this, or I will do that". [The family will say]..."What do you think, Dad? What are you going to do?". ---</i> Medical Oncologist. •
Follow up
<ul style="list-style-type: none"> • <i>I believe the concept of revisiting the decision is about reassuring yourself that you've made the decision that's best for you before it becomes irrevocable... Sometimes you will revisit that decision because you come up with new information... my role there was to listen very carefully and when it was needed to announce what this information really meant for what we had decided and then discuss whether we felt we needed to change the decision---</i> Family member

Table 2: Characteristics influencing family involvement: Illustrative quotations

<p>Patient characteristics</p> <ul style="list-style-type: none"> • <i>I think it [family involvement] is just a very individual thing. I think the gender comes into it... Your generation comes into it and ethnicity comes into it. They all impact---</i> Oncology Nurse • <i>I think it's the more needy patients [who have active family involvement] – the very young and the very old are the most common, or the ones who are physically debilitated and needing the care for physical reasons. And then finally, those who either have a mental health disorder or severe anxiety or depression. ---</i> Medical Oncologist
<p>Relationship characteristics</p> <ul style="list-style-type: none"> • <i>If you are a family member and you are close to that person – if you are a parent or a wife or a spouse or a child...– there's this real feeling of keeping them alive. When it's an elderly lady and their niece comes along, and that's sort of a bit more remote, then you tend to find the decisions are different, and the conversation is a little bit different---</i> Oncology Nurse
<p>Decision characteristics</p> <ul style="list-style-type: none"> • <i>So decisions that are big, complex decisions with long-term ramifications, you need help. I think we all need to be able to... give ourselves some certainty that we're making the right decision, and it's hard to do that in isolation---</i> Medical Oncologist • <i>When it's just operation or not, there is no real decision making then. It's really perhaps nice to have them [family] there, but there are no decisions... It's really 'do you want to die or do you want to have the operation and have a chance of living?'. But in the ones where there is a decisional conflict, then I think [family involvement is] even more helpful---</i> Surgical Oncologist