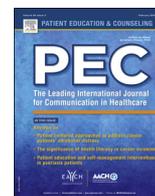




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Review article

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

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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.

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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.

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1. Introduction

Family caregivers regularly attend cancer consultations with an adult patient (accompaniment rates range from 64 to 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 appear 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 5000 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

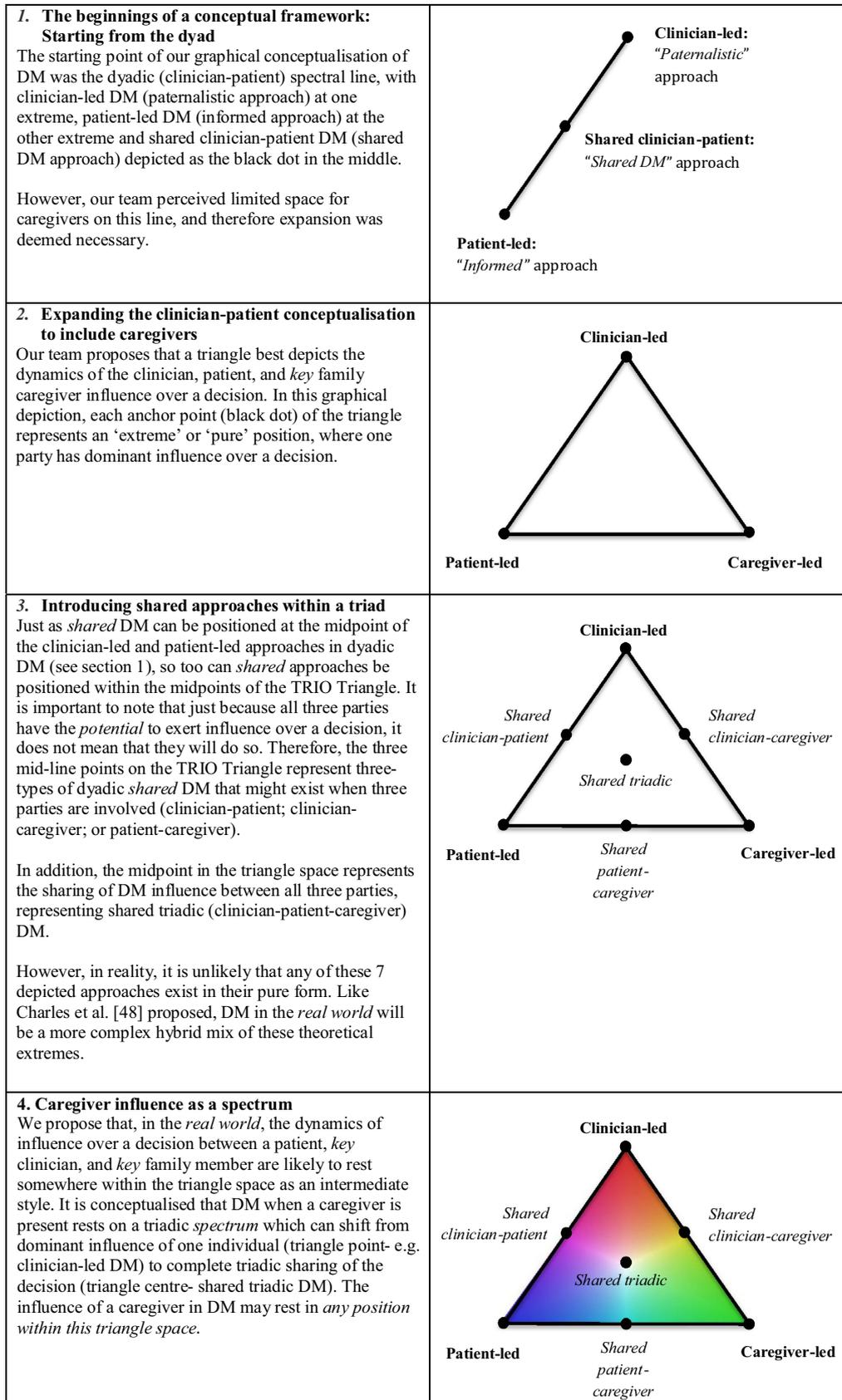


Fig. 1. Developing the TRIO Triangle.

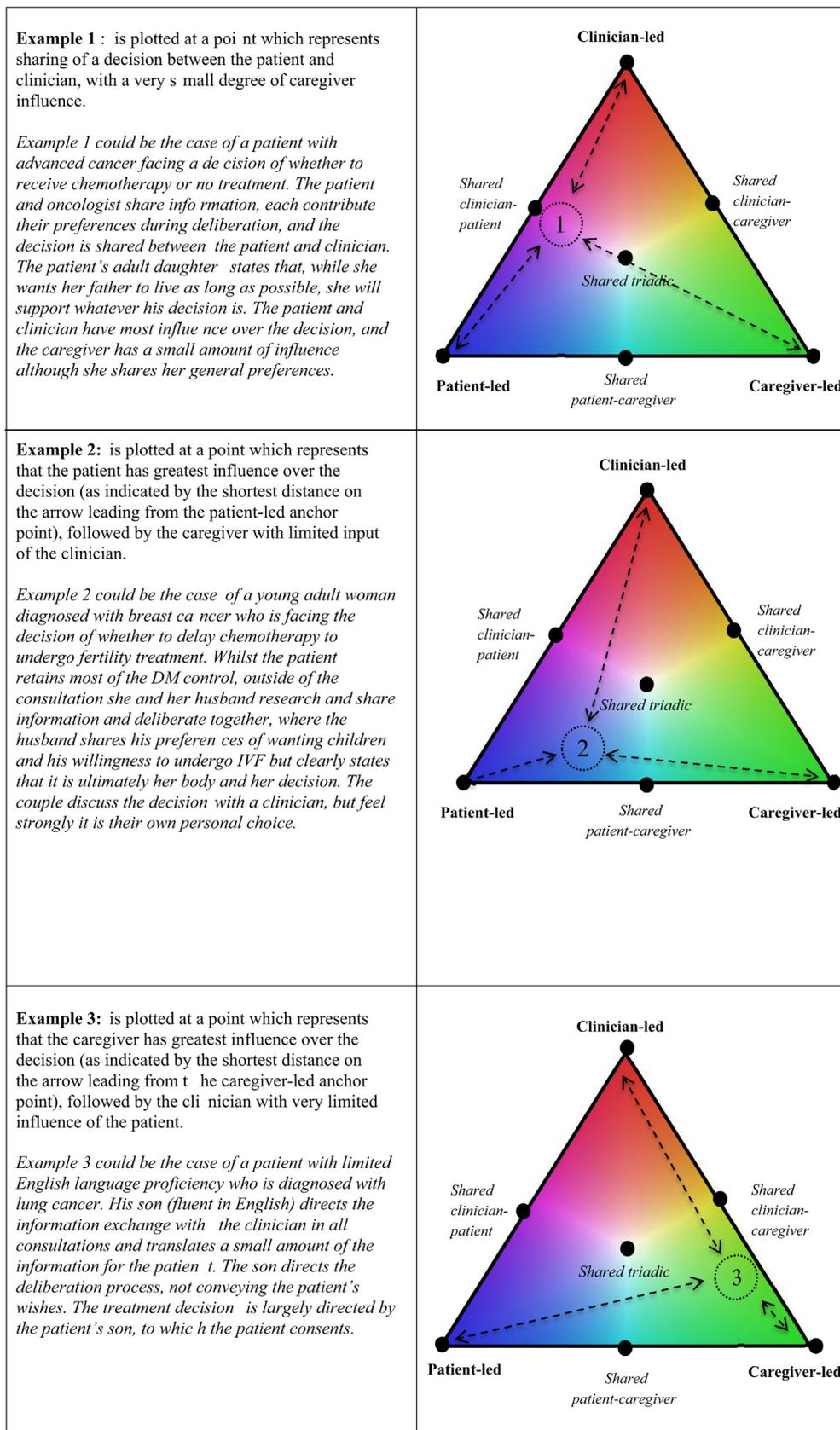


Fig. 2. The variability of caregiver influence amongst different triads.

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 Fig. 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 Fig. 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 Fig. 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 Fig. 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 uni-dimensional 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 Fig. 1, Section 4), versus the 7 "pure" approaches depicted by the points and mid-points of the triangle.

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).

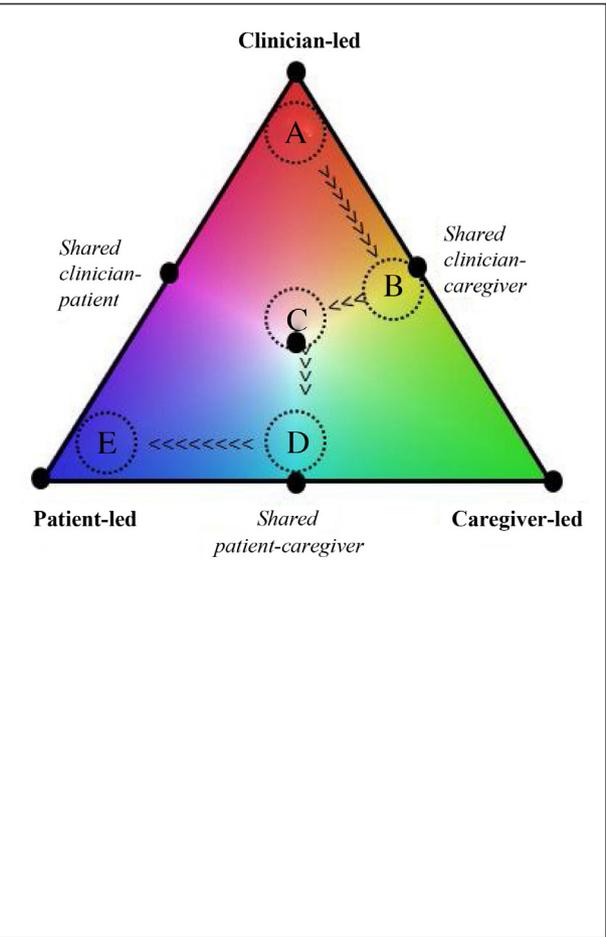


Fig. 3. The variability of caregiver influence within the one triad over time.

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.

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].

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

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 Fig. 3, where points A–E represent different decision points within one patient’s illness trajectory.

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

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

Pre consultation
<ul style="list-style-type: none"> • 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— Family member • We had already made up our mind before we went in there— Family member
Information exchange
<ul style="list-style-type: none"> • 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— Family member
Deliberation
<ul style="list-style-type: none"> • 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— Patient
Decision
<ul style="list-style-type: none"> • 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?”. — Medical Oncologist.
Follow up
<ul style="list-style-type: none"> • 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— Family member

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.

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.

Fig. 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 Fig. 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.

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)

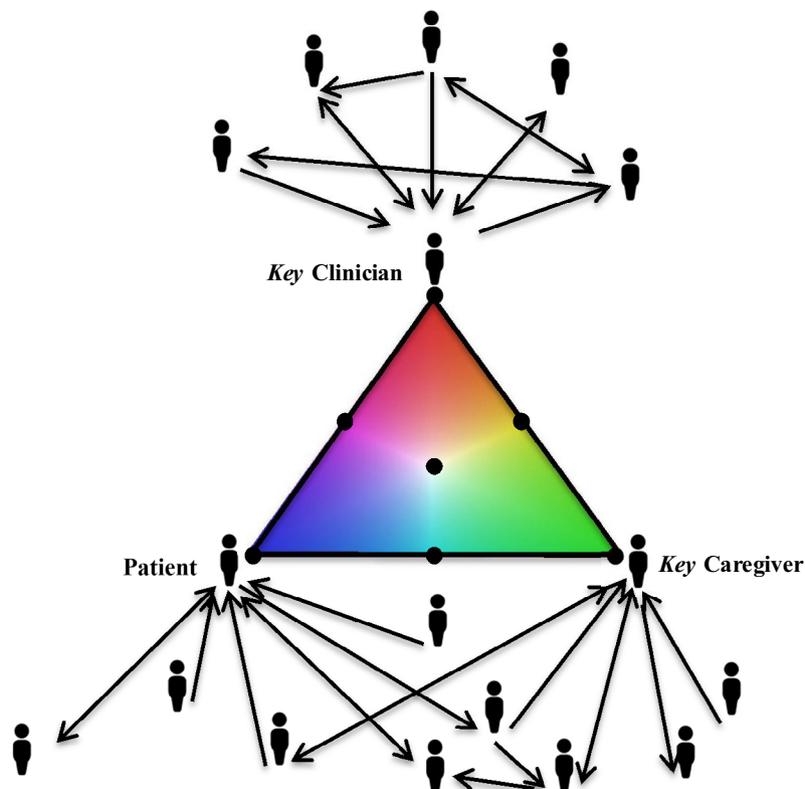


Fig. 4. A hypothetical social network involved in a medical decision.

Table 2

Characteristics influencing family involvement: Illustrative quotations.

Patient characteristics
<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—Oncology Nurse</i> • <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. — Medical Oncologist</i>
Relationship characteristics
<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—Oncology Nurse</i>
Decision characteristics
<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— Medical Oncologist</i> • <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—Surgical Oncologist</i>

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.

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 influences 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 are 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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