



National Hospice and Palliative Care Organization
Palliative Care Resource Series

**UNDERSTANDING THE IMPORTANCE
OF THE INTERDISCIPLINARY TEAM
IN PEDIATRIC HOSPICE AND
PALLIATIVE CARE**

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INTRODUCTION

Decisions for children are best made with input from the various people who care about their unique needs. Pediatric hospice and palliative care is likely to bring special challenges due to the painful and emotionally charged nature of a child's serious illness and impending death. The child, parents, or any member of the health care team may experience some degree of denial regarding the child's situation. For these reasons, it is essential to utilize a team of decision makers in pediatric hospice and palliative care.

The recommendation is that hospice and/or palliative care plans be developed by the child (when appropriate), the child's parents, and the child's physician (Canadian Pediatric Society, 2004). Disease progression in children results in isolation and increased exposure to adult caregivers. As the child matures, she will develop increasing capacity to make her own health care decisions and, thus, should have an ever-increasing role on the health care decision-making team, until she is capable of making fully autonomous health care decisions. Until that time, decision making along the continuum of a child's illness can be greatly enhanced by the input of the pediatric and hospice care interdisciplinary team (IDT).

This paper will give background on the IDT and hospice and palliative care; define the IDT describing the components and challenges and examine the role of the IDT, hospice and palliative care with pediatrics.

UNDERSTANDING THE IDT AND HOSPICE AND PALLIATIVE CARE

IDTs are often synonymous with hospice care and are one of the core elements of hospice and palliative care (Meier & Beresford, 2008). IDT members may include physicians, nurses, chaplains, social workers and volunteers. In some situations, health aides, bereavement counsellors, dieticians and pharmacists are also key members of the team (Wittenberg-Lyles et al., 2007). The developmental needs of children require still more pediatric palliative care or hospice team members including child life, art, music, occupational, physical and speech/language therapists, teachers, lactation consultants and others.

Multidisciplinary vs Interdisciplinary Teams

A PubMed search yields a wide range of definitions of both a multidisciplinary team and an interdisciplinary team. One of the most complete, yet clear and concise, comparison of these models of care is offered by Rebecca Jessup (2007).

A Multidisciplinary team

- Utilizes the skills and experience of individuals from different disciplines.
- Ensures each discipline approaches the patient from its own perspective.
- Involves separate individual consultations. These may occur in a "one-stop-shop" fashion with all consultations occurring as part of a single appointment on a single day.

- Meets regularly, in the absence of the patient, to “case conference” findings and discuss future directions for the patient’s care.
- Provides more knowledge and experience than disciplines operating in isolation.

An Interdisciplinary team (IDT)

- Integrates separate discipline approaches into a single consultation. That is, the patient-history taking, assessment, diagnosis, intervention and short- and long-term management goals are conducted by the team, together with the patient, and at one time.
- The patient is intimately involved in any discussions regarding their condition or prognosis and the plans about their care. A common understanding and holistic view of all aspects of the patient’s care ensues, with the (Jessup 2007).

Although quite different in meaning, the terms “multidisciplinary” and “interdisciplinary” are often used interchangeably when describing types of hospice and palliative care teams. The strength of the IDT may originate in the single consultation model where many, if not all, team members work with the patient and family at the same time. In pediatric hospice and palliative care, engaging the child and family from the onset of care creates a patient empowered to form part of the decision-making process, including the setting of long and short-term goals.

DEFINING THE IDT

Drinka and Clark (2000) created one of the definitions of the interdisciplinary team that would grow to gain wide levels of acceptance by researchers and clinicians alike.

An interdisciplinary healthcare team brings together a group of individuals with diverse training and education to work on an identified task. These healthcare teams can include doctors, dentists, nurse practitioners and registered nurses, occupational therapists, pharmacists, physician assistants, physical therapists, social workers, nutritionists, and clergy. Team members collaborate to address patient problems that are too complex for one discipline, or even many sequential disciplines, to solve. At the most basic level, effective teamwork depends on the ability of members to determine the overall mission, establish shared and explicit goals, and work collaboratively to define and treat patient problems. Ideally, teams can also learn to accept and make use of disciplinary differences, differential amounts and types of power, and overlapping roles to clarify and evaluate the team's development and effectiveness (Drinka & Clark, 2000).

Drinka and Clark’s (2000) definition is inclusive of many variables that are inherent in most IDTs:

- the diverse training and education of team members
- the importance of collaboration
- complexity of patient needs and problems
- the importance of members’ ability to agree upon their overall mission and develop shared goals

- the team's acceptance and utilization of individual team members' differences and power differentials in ways that will be beneficial;
- the opportunity for overlapping roles to clarify the team's growth and development.

This comprehensive definition of the IDT illustrates the many moving parts and uncontrollable components that a team must understand, embrace, and master in order to be effective, efficient, and compassionate.

- First, the issue of bringing together a group of individuals with diverse training and education, which suggests that there may be a variety of opinions regarding both team and patient needs, may present challenges between various team members. When a team is formed, it may be difficult to ensure that each individual understands and/or embraces the training and education of all others at the table. Others' roles may be appreciated only after there have been ample opportunities to observe one another's expertise in action.
- Second, the definition calls on team members to collaborate to address problems that are too complex for one of them, or even several of them, to solve independently. In some circumstances, a team member may not yet recognize his/her need to work collaboratively on complex problems, thinking that he/she may be able to tackle tough problems independently and, thus, not need to work collaboratively. This fluid and interactive process of collaborative communication is facilitated through the IDT meeting (Wittenberg-Lyles & Parker Oliver, 2007).
- Next, Drinka and Clark's definition of IDTs challenges the members of the IDT to determine the team's overall mission and establish shared goals that will enable them to work collaboratively in providing the best patient care. When the reader considers the task of developing an overarching mission and shared goals which lead to effective collaboration, the analogy of a simmering pot of soup comes to mind, where each ingredient provides a unique flavor, while all ingredients are blending to offer the robust taste that is THE SOUP. Similarly, the individual's training and education must rise to the top and offer its own unique flavor, while simultaneously blending into the simmering pot of shared flavor, or goals.
- Finally, the authors refer to the disciplinary differences, power differentials, and overlapping roles that may enhance the team's growth and development. The similarities are in the components—the social worker, nurse, chaplain, physician. The team includes members who have learned to use the unique talents of others in new ways, while embracing the team's power differentials and clarifying the team's defining qualities which enable them to share roles and responsibilities. Thus, the IDT emerges as a well-oiled machine, consisting of a variety of moving parts, but parts which move smoothly around one another to create the reality of a single machine that operates effectively.

Components of the IDT

Nancarrow and colleagues (2013) sought to identify what, specifically, defined effective IDTs. Their research involved a systematic review of the literature on IDTs as well as the responses of 253 staff from 11 community care teams in the United Kingdom. The data sources were then merged using

qualitative content analysis which led to the identification of characteristics that are present when effective IDT work is practiced. Finally, they proposed ten competencies that support effective interdisciplinary teamwork. These competencies are proposed, by the study authors, as those which illustrate an effective IDT which is functioning at a high level. Those competencies and a brief description are provided here.

- **Leadership and management attributes:** Identifies a leader who establishes a clear direction and vision for the team, while listening and providing support and supervision to the team members.
- **Communication strategies and structures:** Incorporates a set of values that clearly provide direction for the team's service provision; these values should be visible and consistently portrayed.
- **Personal rewards, training and development:** Demonstrates a team culture and interdisciplinary atmosphere of trust where contributions are valued and consensus is fostered.
- **Appropriate resources and procedures:** Ensures appropriate processes and infrastructures are in place to uphold the vision of the service (for example, referral criteria, communications infrastructure).
- **Appropriate skill mix:** Provides quality patient-focused services with documented outcomes; utilizes feedback to improve the quality of care.
- **Supportive team climate:** Utilizes communication strategies that promote intra-team communication, collaborative decision-making, and effective team processes.
- **Individual characteristics that support interdisciplinary team work:** Provides sufficient team staffing to integrate an appropriate mix of skills, competencies, and personalities to meet the needs of patients and enhance smooth functioning.
- **Clarity of vision:** Facilitates recruitment of staff who demonstrate interdisciplinary competencies including team functioning, collaborative leadership, communication, and sufficient professional knowledge and experience.
- **Quality and outcomes of care:** Promotes role interdependence while respecting individual roles and autonomy.
- **Respecting and understanding roles:** Facilitates personal development through appropriate training, rewards, recognition, and opportunities for career development. (Nancarrow 2013).

It is interesting to note that, within these ten recommended competencies of an effective IDT, Nancarrow and colleagues include each of the topics identified in the definition of an IDT provided by Drinka and Clark (2000). Thus, some fifteen years after the concept of IDTs in hospice and palliative care has become commonplace, the consistency in what defines an effective, efficient, and compassionate IDT has also gained consistency in definition and in practice.

Challenges of the IDT

It is not surprising, however, that there are challenges to the IDT even when the recommended characteristics of the IDT, as suggested by Nancarrow and colleagues, are included in the make-up of the team. Often, difficulties may arise as a result of an individual's difficulty in understanding the importance of the requisite team characteristics. Or, perhaps a team member does not perceive that he or she is a valued member of the team. If there is a real, or perceived, power differential,

the team may be experiencing a real threat to its viability. Despite growing recognition that there is a real or perceived power differential in IDTs and that this phenomenon may be used to strengthen the team, a power differential within a team may also create difficulties in how team members are perceived or how they perceive their own value.

Reese and Sontag (2001) reported practices that may undermine the IDT and offered solutions that may ensure the team's success. Several potential barriers were highlighted by the researchers, any of which may compromise the effectiveness of an IDT, and which include:

- lack of knowledge of the expertise of other professions
- lack of commitment to the team process,
- lack of willingness to take on an equal share of the team's work,
- IDT members' lack of understanding of one another's expertise,
- role blurring,
- theoretical differences
- power differentials on the team,
- scapegoating
- client stereotyping
- value based conflicts between different professions,
- negative team norms
- administrative issues

One example of a barrier and associated solution was related to the perception, by other team members or social workers themselves, that social work may be viewed within hospice as ancillary or secondary to medicine. Suggested solutions included orienting the team, either at orientation or in continuing education, to each professional's role to ensure full understanding and appreciation of each profession. A commitment to the IDT from administration, or a strong team leader, may ensure that this type of education and appreciation has the potential to be fully developed.

Recent attention, in both research and practice, has been given to the potential problems that may arise in the intimate setting of a patient's journey toward death. Both the intensity of the situation, as well as the time-limited need to build effective working relationships between professionals and patient/family members, creates the perfect storm for difficulty in maintaining a therapeutic relationship.

Patients and families are often very grateful for the support they receive from the hospice or palliative care team, thus resulting in their desire to give something to the professional to express their gratitude. Parents of children who die may feel a connection with the hospice team that is difficult to relinquish and parents may, therefore, attempt to maintain a relationship that takes on the definition of friendship with certain hospice team members. Boundary issues surface when professionals are faced with a "second role," or dual relationships with clients (Reamer, 2003). Professional boundaries have the advantage of providing not only protection for the patient/family, but also for the professional (Homan, 2006a, 2006b).

It has been suggested by some that self-disclosure may be beneficial in relationship development, while others warn that crossing professional boundaries creates a risk to maintaining the focus on the client (Hepworth et al, 2010). Over-identification with the client, accepting gifts from the client, or going “over and beyond” to help the client when not on duty, may be behaviors that warrant support and mentoring for the professional (Dugan Day, 2012).

Peer supervision and support can help define the team’s strength while promoting trust among team members. In addition, specific training and education regarding professional boundaries in hospice and palliative care could be an integral portion of orientation and on-boarding for new palliative care and hospice professionals (Dugan Day, 2012). Strong IDTs include members who can provide support for one another and who can offer guidance to fellow team members if boundary issues become evident.

PEDIATRIC PALLIATIVE CARE AND HOSPICE AND THE IDT

In pediatric palliative care and hospice, the IDT is an integral part of the concept of patient and family centered care. In the National Hospice and Palliative Care Organization’s (NHPCO) Standards of Practice for Pediatric Palliative Care and Hospice (2009), the first principle of patient and family centered care states:

The palliative care and/or hospice interdisciplinary team provides family centered care that includes the child and family as one unit of care, respecting individual preferences, values and cultural beliefs, with the child and family active in decision making regarding goals and plan of care” (NHPCO, 2009). Understanding the IDT is a first step in creating, growing and maintaining an effective, efficient, and compassionate care for children and families.

Are there unique issues regarding the importance of the IDT in pediatric palliative care and hospice?

The answer to this question originates in the definition of pediatric palliative care and, further, informs the practice of pediatric hospice care. The Section on Hospice and Palliative Medicine (SOHPM) of the American Academy of Pediatrics (AAP) definition of palliative medicine includes the following.

The focus of pediatric palliative care is to enhance the quality of life for all involved, in large part by preventing and alleviating suffering using the skills and knowledge of a specialized care team that includes doctors, nurses, social workers, chaplains, child life therapists, and others. Pediatric palliative care focuses on pain and symptom management, information sharing and advance care planning, practical, psychosocial and spiritual support, and coordination of care. (AAP, 2015).

This definition of pediatric palliative care speaks of “enhancing the quality of life for all involved” and of using the skills and knowledge of “a specialized care team that includes doctors, nurses, social workers, chaplains, child life therapists and others.” The definition goes on to include that the discipline “focuses on pain and symptom management, information sharing, advance care

planning, practical, psychosocial and spiritual support and coordination of care.” This includes a wide range of professionals who are learning to work together in the best interest of children and families.

Nowhere in this definition is it suggested that a single professional or that only medical providers, for example, will suffice in providing the type of support that defines pediatric palliative care. It does suggest, however, that a wide range of professionals should be responsible for addressing the planning, practical, psychosocial, and spiritual support and coordination of care for the child and family. Due to the growth and development experienced in childhood, the IDT may even extend beyond the health care professionals involved with the child and family. Teachers, coaches, youth pastors, scout leaders, dance teachers and a host of other caring adults who are involved in the child’s life may also contribute, in some situations and to a lesser extent than the health care team, to ensuring that the child’s quality of life remains intact.

Thus, the AAP definition of pediatric palliative care states that it takes the entire IDT to provide the care that is needed when a child has a serious or complex pediatric diagnosis. Utilizing the expertise of a wide range of providers ensures that there is always someone who is available to attend to the challenging and ever-changing needs of the child and family.

There continues to be a lack of data to define achievements of pediatric providers and programs. Consensus has not been reached within the pediatric palliative care field to standardize the methods of defining, measuring and analyzing effectiveness of providers and programs and barriers have been identified to achieving standardization (Kaye, Abramson, et al. 2017). Developing metrics to effectively measure productivity of professionals and programs is critical to ensuring that the IDT is achieving recommendations of the AAP and providing optimal care to children and families.

CONCLUSION

Denial, emotional upheaval and lack of knowledge about what may lie ahead results in making palliative or hospice health care decisions, and the ensuing experience for children and families, extremely difficult for all parties. It is a situation that is incomprehensible to most children and their family members and a journey that is poorly defined for the family. The expertise, experience and compassion of the IDT is of utmost importance a child and family.

Honest, on-going communication among team members, and between the team and family receiving care, creates the foundation for the development of the IDT. Each IDT should include general components recommended for all IDTs, in a manner specific to each unique team.

Creating and maintaining a strong framework for the IDT will ensure that the likely challenges that all teams encounter will not threaten the continuation and effectiveness of the team. Combining a clear understanding of what an IDT is, and is not; focusing on the characteristics that contribute to a strong IDT; and recognizing ways that each member may increase the knowledge and expertise needed to be the best IDT member possible are all strong pathways to being part of the IDT solution, not the IDT problem.

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