

Including Adolescents and Young Adults in Decisions at the End-of-Life

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Abstract

Over 3000 young people die of chronic illnesses annually in the United States. Health care providers often struggle to include these patients in end-of-life planning. The purpose of this inquiry is to examine the current literature addressing the inclusion of adolescents and young adults in decision-making at the end-of-life. A systematic search of the electronic databases PubMed, Scopus, CINAHL, ISI, and Cochrane revealed 9 articles relevant to this topic. The results show that adolescents and young adults want to be included in end-of-life decisions and often have similar values as their parents and providers when making these decisions. The major limitations are the limited population sample of the studies, in terms of size and patient characteristics, and inconsistencies with the ages of participants in the studies. Ideas for further research, in addition to implications for clinical practice will be discussed in this paper.

Adolescence is a time when young people exert their autonomy, attempt to form their own identity and independence, and develop a greater sense of their sexuality that occurs from hormonal and physical changes. Adolescents may also view death in a more adult-like manner by understanding that it is a permanent and universal part of life. Adolescents who face their own mortality as a consequence of life-threatening illnesses have an even greater depth for appreciation of this universal experience at an even earlier age than their healthy peers (Freyer, 2004).

Annually in the United States, over 3,000 adolescents die from chronic illnesses, including cancer, metabolic disorders, renal disease, and heart disease (Freyer, 2004). Despite the possibility of death from life-threatening illnesses, health care providers often delay talking to young patients about dying (Lyon et al., 2009; Wiener et al., 2008). Research shows, however, that young people want to talk about their preferences and values at the end-of-life (Lyon et al., 2009). In fact, research demonstrates that by the time children reach adolescence, they are capable of having mature discussions and processing information with a level of thinking similar to an adult (Zinner, 2009). Recognition of this desire and maturity warrants the inclusion of adolescents in discussions about end-of-life care with the onus on health care providers to find effective ways to start these discussions and engage adolescents in need to consider how to incorporate them into the decision-making processes for determining preferences for treatment options.

In the United States, people generally are deemed to be legally competent at age 18 years,

and have autonomy to consent to or refuse medical care. Those under age 18, however, generally cannot legally make independent decisions, which present unique challenges in giving them the authority to self-determine the course of medical care. Adolescents younger than 18 who are facing death from progressive diseases are often educated about their illnesses and have preferences for end-of-life treatment (Freyer, 2004). In addition, there are laws in most states in the US that allow minors in certain circumstances to make their own medical decisions, such as those who have gone to college, those who are pregnant, and those seeking care for sexually transmitted illnesses or substance abuse (Freyer, 2004; Zinner, 2009). Although there are no legal requirements imposed for including minors in end-of-life decisions, there is broad consensus among pediatric health professionals, lawyers, and ethicists that adolescents 14 and older, and maybe as young as 10, are functionally capable to make their wishes known and to actively participate in medical decisions at the end-of-life (Freyer, 2004).

Older adolescents and young adults face the same challenges with end-of-life decisions (Wiener et al., 2008). Adolescents and young adults with terminal illnesses may mature socially slower than their healthy peers in some ways, due to issues such as parental overprotection, social isolation leading to low self esteem, and delays in forming sexual relationships (Freyer, 2004). The fact remains that much of the research addressing end-of-life decisions by adolescents includes those up until 21 years of age and older taking into account that similar challenges exist for both older adolescents and young adults compared

to their younger peers.

This paper addresses the following question: How can health care providers include adolescents and young adults in decision-making at the end-of-life? This question will be answered through a thorough evaluation of the current literature on the topic.

Methods

The literature review was structured to find research articles about adolescents and young adults and their involvement in end-of-life decision-making. Five online databases, PubMed, Cumulative Index for Nursing and the Allied Health (CINAHL), ISI Web of Knowledge, Cochrane Library, and Scopus were systematically searched for this paper. Six searches were performed in PubMed using Mesh search terms such as “adolescents and end-of-life decisions” (114 articles), “teenagers and end-of-life decisions” (114 articles), “young adults and end-of-life decisions” (47 articles), “adolescents and advance directives” (165 articles), “teenagers and advance directives” (165 articles), and “young adults and advance directives” (46 articles). Due to the small number of studies available for this new topic of research, articles were included since the year 2000. Limits placed on all of the searches were 1) English language; 2) human research; 3) research articles since 2000; and 4) ages 13-18 and 19-24. Results were excluded if they were not research articles, if they were not on topic, if they were not relevant to the United States, if they were not specific to adolescents and young adults, or if they only discussed parents’ participation in decision-making. Seven research articles were identified that met all inclusion criteria from the above searches. Similar searches were performed using CINAHL, ISI Web of Knowledge, and Cochrane Library databases, which resulted in no additional relevant articles.

Search terms within Scopus included end-of-life decisions and adolescents. Limits placed on the search included 1) research articles since 2000; and 2) nursing and medical journals only. 212 articles were found from the search. Articles were excluded if they did not meet inclusion criteria or if they were duplicates. Two additional research articles were identified. Finally, the abstracts of all reference lists of the articles to be included in the manuscript were hand reviewed to identify additional relevant studies. No research articles were added from this search. In total, nine research publications met all of the eligibility criteria for inclusion into this paper. Numerous review

articles were used to expand the literature for understanding end-of-life decision-making in adolescents and young adults.

A table of evidence presents all nine research articles, which reports the purpose, study design, population, setting, findings, strength and quality, and major limitations of the studies. Based on the available evidence, major themes were extracted to answer the inquiry question of interest.

Results

The results of the literature search identified several important opportunities and resources to engage adolescents and young adults in decision-making around treatment options at the end-of-life. First, the use of advance directives and other end-of-life planning documents provide the structure for initiating conversations regarding a patient’s wishes to continue or forgo life-prolonging therapy. Second, the comfort level and interest of the patient related to discussions about end-of-life must be assessed, and issues should be raised and addressed that are of greatest concern to adolescents and young adults. Third, patient refusal or lack of acceptance of life prolonging treatments must be respected and incorporated into plans of care. Lastly, congruence between the preferences of patients and their parents and health care providers must be considered in reaching a mutually goal for plans of care.

Advanced planning

Advance directives (ADs) are legal documents that are executed at a time when a person is deemed mentally competent to express the desires and wishes for future care. ADs are honored even when individuals are no longer considered mentally capable of making informed decisions about their health care. For adolescents under 18, there is currently no such legally binding document that allows them to make their wishes and desires for future care known. The concept of the AD is an important one, even with minor adolescents considered mature enough to be included in medical decisions (McAliley, Hudson-Barr, Gunning, & Rowbottom, 2000). However, opportunities to legitimize their wishes for future treatments are limited.

Several studies have examined whether adolescents and young adults feel ADs and other advanced planning documents are necessary and helpful. In one study involving interviews with healthy and ill teenag-

ers about ADs, McAliley et al. (2000) found that the majority of participants think that ADs are important for people their age who have chronic conditions, life threatening illnesses, and those undergoing risky surgery. The majority of participants also thought that it was important for someone of their age and health to have ADs. Wiener et al. (2008) explored whether adolescents and young adults find it helpful to have Five Wishes©, an advanced planning document usually used by adults, available to them to discuss end-of-life decisions. Most (95%) reported that the document would be helpful for them, and 90% believed that it would be helpful to individuals their own age with a serious illness to make their wishes known.

Studies that explore adolescent and young adult decision-making find that young patients are able to verbalize their preferences in meaningful ways to inform parents and health care professionals of their desires to have certain therapies to sustain life. For example, McAliley et al. (2000) presented participants with a scenario of a patient in a coma and asked them what they would want done for themselves if they were in the same situation. The majority of respondents chose major surgery, antibiotics, intravenous (IV) fluids, and a feeding tube, while less than half opted for a ventilator and cardiopulmonary resuscitation (CPR) life sustaining interventions. Hinds et al. (2005) interviewed 20 adolescents about a recent end-of-life decision they had made, either enrolling on a phase I trial, signing a do not resuscitate (DNR) order, or initiating palliative symptom management. All but two of the participants were able to verbalize the options that were offered to them when making the decision, and participants were able to articulate their thought processes for making the decision and weighing the likely outcomes.

Comfort level of patient

Health care providers frequently report feeling uncomfortable discussing end-of-life issues with young people, for fear of causing anxiety and diminishing hope (Lyon et al., 2009; Lyon, McCabe, Patel, & D'Angelo, 2004; Wiener et al. 2008). However, studies of the patients themselves indicate that they are actually comfortable having these discussions about their preferences at the end-of-life, and want to be included in such decisions.

McAliley et al. (2000) found that most teenagers interviewed felt comfortable talking to the researchers about end-of-life decision-making. Overall,

none of the participants interviewed by Wiener et al. (2008) perceived the overall discussion about Five Wishes© to be stressful, although there were certain items that some participants did find stressful, such as the wish for specific type of life support treatments given. Overall, participants did not feel stressed enough to stop the interview, instead they offered suggestions as to how to make the question easier for them understand.

In several of the studies, participants reported that they wanted to be included in end-of-life decisions. Lyon et al. (2004) interviewed both healthy and chronically ill adolescents to determine if differences exist between how they view end-of-life issues. The majority of these adolescents stated that they would want to share in decision-making if they were in a circumstance that required end-of-life discussions. Pousset et al. (2009) conducted interviews with adolescent cancer survivors about their thoughts on end-of-life issues by using hypothetical scenarios. The majority of the participants, 86%, stated that they would want to be told of the severity of their condition if their disease became terminal. Also, 96% of the participants emphasized that minors in general have the right to be informed whether their condition is terminal. Findings from studies done by Hinds et al. (2001, 2005) supported the contention that adolescents with cancer want to be well informed of their illness and treatment options in order to be included in decision-making around their care.

Comparison of patient, parent, and provider preferences

An important consideration when dealing with the decisions of young patients is how these decisions fit with the preferences of their parents and health care providers. Lyon et al. (2009) looked at the effect of family/adolescent-centered advanced care planning (FACE) on the quality of communication and congruence between patients with HIV and their family members. Adolescents and their guardian or surrogate in the FACE group participated in a series of interviews to determine whether the patient wanted to be included in end-of-life decision-making and determine their experience with their illness and death and dying. Each completed a Five Wishes© document. Adolescents and their guardian or surrogate in the control group participated in a developmental interview, were given counseling on health promotion, and participated in a discussion about future plans for education or work.

In two out of the three scenarios, patients and their guardians or surrogates showed higher congruence in the FACE group than the control group. When examining the preferences of adolescents with advanced cancer who had recently made an end-of-life decision, Hinds et al. (2005) established that the majority of patients, parents, and physicians had similar views as to the treatment choices. All three parties agreed that considering the preferences of others, preventing or reducing suffering, and ensuring that all treatment options are exhausted is critical to reaching to end-of-life treatment decisions. Similarly, Hinds et al. (2001) identified that adolescents, their parents, and health care providers want to know that all curative therapies have been tried before making end-of-life choices, and want to balance remaining life with suffering and potential adverse events. Overall, the literature supports that preferences of patients balanced with those of their parents and providers can minimize conflicts that arise when decisions are not transparent and based on considering the perspectives of patients, families and health care professionals.

Talati, Lang, and Ross (2010) studied who health care providers perceive to be the primary decision maker when working with adolescents. With 11 year olds, the majority of physicians thought that the parent was the primary decision maker, versus with 16 year olds where 58% believed that the adolescent assumed this role. Lyon et al. (2004) evaluated whether or not patients believe their providers will respect their decisions. Eighty percent of chronically ill adolescents and 68% of healthy adolescents believed that their health care providers would respect their preferences at the end-of-life. These findings underscore the importance of clarity around perceived primary decision makers. If health care providers do not think that the patient is the primary decision maker, they may be less likely to include the adolescent in end-of-life decisions. Also, if patients themselves do not trust their providers to respect and value their input, they may be less likely to be forthcoming in making their wishes known and participating in decisions that will determine the course of care.

Refusal of treatment

The ability of minor adolescents to refuse treatments that might not benefit them or cause undue suffering is another factor to consider. Competent adults age 18 and older have the right to not only consent to treatment but to also refuse such treatment, even if the

refusal would result in their death. Interpretations of current laws preclude young adolescents from giving legal consent to treatment, however, research is emerging to challenge the constraints placed on treatment consent by young adolescents (Lemmens, 2009). As such, the opinions of the legal system and health care providers are presented to illustrate debates regarding patients' ability to refuse futile treatments or those with limited benefits of leading to optimal outcomes in the end stages of diseases.

Legal System. Lemmens (2009) performed a comparative study of case law from six countries to see if mature minors are allowed to refuse life saving medical treatment. The results from this study yielded interesting findings. Although the legal systems across recognize the mature minors' rights to consent to and refuse medical care, there is still hesitancy to allow a minor to refuse treatment when it would result in their death. Statutes enforced by courts state that preservation of the minor's life is more important than honoring their preferences for care. This is an interesting phenomenon, because if the courts consider a minor mature enough to make certain medical decisions such as treatment for sexually transmitted illnesses and treatment for alcohol and drug use, questions are then raised as to why there are not existing provisions to allow minor to make other mature medical decisions at the end of their life.

Health care providers and patients. Although the court systems would deny an adolescent's request for refusal of life sustaining care, research shows that health care providers would accept the refusal of the patient and the parent in several circumstances. Talati et al. (2010) found that when the prognosis is good, physicians would generally deny a request for refusal of care, but when the prognosis is poor, they are more likely to respect the patient or his parent's wishes for refusal of care, especially if the patient is 16 or older. Pousset et al. (2009) studied adolescent cancer survivors' views on withdrawing life sustaining treatment using hypothetical scenarios. Similar to health care providers, adolescents accept the decision to withdraw or withhold treatment in terminal situations more often than in non-terminal situations.

Analysis of the Literature

Investigations on including adolescents and young adults in end-of-life decision-making are limited, in part because this is an emerging area of research. The majority of studies still focus on how par-

ents make decisions for their children, and fall short of considering the capabilities of adolescents and young adults in predetermining their course of treatment or withdrawal of life-sustaining therapies. Additionally, there is a significant gap in the science to guide processes for engaging younger but capable patients in decisions at the end-of-life. Studies that do exist vary in levels of scientific quality and rigor. The nine studies identified for analysis ranged from research-based guidelines to randomized control trials (RCTs). Comparative, exploratory and qualitative studies along with publications involving descriptive interviews add to the body of evidence to better understand how younger persons with progressive, life-threatening illnesses can contribute to decisions around their care.

Since only one of the studies was a controlled study, the body of evidence is mostly graded as level III, based on The Johns Hopkins Nursing Evidence-Based Rating Scales. In addition, the majority of evidence is graded as quality of B (Newhouse, Dearholt, Poe, Pugh, White, 2005). For the most part, study findings are fairly consistent in the results and conclusions. In many cases, recommendations for practice are only partially based on scientific evidence from literature reviews, which is expected as the science in this area is evolving and there is not a strong evidence base to formulate universally accepted guidelines. As more research is conducted in the field of end-of-life decision-making with adolescents and young adults, it is likely that evidence-based guidelines will support and direct the active involvement of adolescents and young adults in pre-determining treatment options and course of clinical care.

Limited patient population

Disease focus. One of the limitations of this inquiry is the focus on specific diseases. Six of the studies interviewed only patients with cancer or HIV, or their parents or providers. The heavy focus on these illnesses makes it difficult to generalize the data to all adolescents and young adults. Since people with other conditions may approach end-of-life decisions differently than their peers with cancer and HIV, data obtained from the above studies cannot be generalized to all young patients with life-limiting diseases.

Approachability. In addition to disease focus, only patients and their parents who were willing to talk about end-of-life issues with the researchers were approached. In some studies, such as Hinds et al. (2005; 2001), only patients who had recently made a

major end-of-life decision were approached. This may have created a bias, because adolescents and young adults who have been actively involved in a decision or who are interested in talking about end-of-life choices may have different opinions regarding their participation in the decision than patients who are unwilling to talk about it with researchers.

Small sample size. Finally, all of the studies had small sample sizes, making it difficult to generalize the data. Most of the studies had strict inclusion criteria, utilizing small patient populations. In addition, since most of the studies involve in depth interviews about end-of-life decisions, which can be difficult conversations, many people who are approached are not comfortable participating, which further limits the sample size. Most of the sample sizes were under 100 patients, with some of them Wiener et al. (2008) and Hinds et al. (2005) including only 20 patients each.

Inconsistent ages

Another reason the research is limited is because of the lack of clarity of definitions regarding the ages of patients used. While most studies define the terms adolescents, young adults, and mature minors, the definitions differ in all of them. There is no standard definition for any of the age groups. For example, Pousset et al. (2009) describes adolescence as 11 to 18, while Lyon et al. (2004) describes adolescence as 12 to 21 years. Adolescence is a time of great growth and maturation, and by grouping all of adolescence into the same studies, it is difficult to generalize recommendations to specific ages of adolescents who will approach end-of-life decisions differently based on their developmental level.

In addition to the differing definitions of the age groups, most of the studies did not include young adults. Wiener et al. (2008) is the only study that interviewed young adults up to 28 years old. McAliley et al. (2000) interviewed teenagers but asked for their opinions on advance directives in young adults 18 to 29 years old. The rest of the studies looked at adolescents and mature minors. Since there is not more data on young adults in the studies, and a 26 year old clearly will approach end-of-life decisions differently than a 12 year old, the inquiry cannot be generalized to all young adults making end-of-life decisions.

Strengths

This body of literature is strongest in its focus

on the patients themselves, as opposed to the preferences of the parents and health care providers. Several of the studies included parents and health care providers, in addition to the patients, to determine if there is congruence between their thought processes in regards to end-of-life decisions (Hinds et al., 2005; Hinds et al., 2001; Lyon et al., 2009). This adds strength to the literature, since adolescents under the age of 18 cannot legally make these decisions without their parents, and even once adolescents and young adults have reached age 18 parents are usually still included in the decision process.

Recommendations

Implications for Practice

The above results have important implications for practice when dealing with adolescents and young adults. Although formal discussions with patients regarding end-of-life decisions may be designated to a specific member of the health care team, nurses are often responsible for having conversations with their patients about these issues (McAliley et al., 2000). Nurses may be the first people to initiate conversations with young patients about end-of-life issues. If health care providers are aware that patients wish to have discussions about their end-of-life preferences, they may be more likely to talk about this difficult topic with them.

Health care providers may be concerned that having end-of-life conversations with their patients will cause conflict, if patients and parents do not agree. The literature as a whole shows that young people and their parents have similar desires at the end-of-life and have a high level of congruence when making end-of-life decisions. Health care providers should use this knowledge to include adolescent and young adult patients in end-of-life planning, and take a more family centered approach to allow everyone to express their desires.

Implications for Research

There are several gaps in research pertaining to how adolescents and young adults participate in end-of-life decision-making. The overall strength of such research could be substantially improved by increasing the sample sizes of individual studies. Also, although qualitative research is very useful for this field, including more RCTs would strengthen the quality of the research. In addition, more studies including young adults and studies separating out adolescents

into groups of younger and older participants would strengthen the existing research, as adolescence and young adulthood is a wide range that incorporates people of many different developmental stages. Since the most common causes of death in adolescents and young adults are accidents, homicide, and suicide (Freyer, 2004), more studies similar to Lyon et al. (2004) that look at healthy young people's views of end-of-life issues are important, since healthy young people may eventually be in a situation where they cannot participate in medical decision-making. Wiener et al. (2008) looked at whether adolescents and young adults find the Five Wishes© document to be helpful and appropriate, but further studies looking at whether this age of people fully understands the medical terminology presented in these adult documents is crucial. Finally, research is needed to look at whether including adolescents and young adults in end-of-life decision-making allow their wishes to be respected.

Conclusion

Although there are limited empirical data to support end-of-life decision-making including adolescents and young adults, studies that do exist have important implications for clinical practice which will be expanded as further research is conducted. The literature shows that adolescents and young adults can and want to be included in decision-making at the end-of-life, whether this is through the use of advance directives, refusal of treatments, or in depth conversations about their preferences. Even with young patients, health care providers should have a strong patient-centered approach to care, where the patient is an active member in their own health care. Health care providers can nurture the dying adolescent and young adult's growing autonomy by including them in their own end-of-life decision-making.

References

- Freyer, D.R. (2004). Care of the dying adolescent: special considerations. *Pediatrics*, *113*(2), 381-388. doi:10.1542/peds.113.2.381
- Hinds, P. S., Drew, D., Oakes, L. L., Fouladi, M., Spunt, S. L., Church, C., & Furman, W. L. (2005). End-of-life care preferences of pediatric patients with cancer. *Journal of Clinical Oncology*, *23*(36), 9146-9154. doi:10.1200/JCO.2005.10.538
- Hinds, P.S., Oakes, L., Furman, W., Quargnenti, A., Olson, M.S., Foppiano, P., & Srivastava,

- D.K. (2001). End-of-life decision-making by adolescents, parents, and health care providers in pediatric oncology: research to evidence-based practice guidelines. *Cancer Nursing*, 24(2), 122-34. Retrieved from <http://journals.lww.com/canceronline/pages/default.aspx>
- Lemmens, C. (2009). End-of-life decisions and minors: do minors have the right to refuse life preserving medical treatment? A comparative study. *Medical Law Review*, 28(3), 478-97. Retrieved from <http://medlaw.oxfordjournals.org/>
- Lyon, M.E., Garvie, P.A., McCarter, R., Briggs, L., He, J., & D'Angelo, L.J. (2009). Who will speak for me? Improving end-of-life decision-making for adolescents with HIV and their families. *Pediatrics*, 123(2), 199-206. doi:10.1542/peds.2008-2379
- Lyon, M.E., McCabe, M.A., Patel, K.M., & D'Angelo L.J. (2004). What do adolescents want? An exploratory study regarding end-of-life decision-making. *Journal of Adolescent Health*, 35(6), 529 e. 1-6. doi:10.1016/j.jadohealth.2004.02.009
- McAliley, L.G., Hudson-Barr, D.C., Gunning, R.S., & Rowbottom, L.A. (2000). The use of advance directives with adolescents. *Pediatric Nursing*, 26(5), 471-80. Retrieved from <http://www.pediatricnursing.net/>
- Newhouse R, Dearholt S, Poe S, Pugh LC, White K. (2005). The Johns Hopkins Nursing Evidence- based Practice Rating Scale. Baltimore, MD, The Johns Hopkins Hospital; Johns Hopkins University School of Nursing.
- Pousset, G., Bilsen, J., De Wilde, J., Benoit, Y., Verlooy, J., Bomans, A.,... & Mortier, F. (2009). Attitudes of adolescent cancer survivors toward end-of-life decisions for minors. *Pediatrics*, 124(6), 1142-8. doi:10.1542/peds.2009-0621
- Talati, E. D., Lang, C. W., & Ross, L. F. (2010). Reactions of pediatricians to refusals of medical treatment for minors. *Journal of Adolescent Health*, 47(2), 126-132. doi:10.1016/j.jadohealth.2010.03.004
- Wiener, L., Ballard, E., Brennan, T., Battles, H., Martinez, P., & Pao, M. (2008). How I wish to be remembered: the use of an advance care planning document in adolescent and young adult populations. *Journal of Palliative Medicine*, 11(10), 1309-13. doi:10.1089/jpm.2008.0126
- Zinner, S. E. (2009). The use of pediatric advance directives: A tool for palliative care physicians. *American Journal of Hospice and Palliative Medicine*, 25(6), 427-430. doi:10.1177/1049909108322294