# Adolescent classroom education on knowledge and attitudes about deceased organ donation: A systematic review

Li AH-T, Rosenblum AM, Nevis IF, Garg AX. Adolescent classroom education on knowledge and attitudes about deceased organ donation: A systematic review.

Abstract: In many countries, adolescents can choose to register a deceased organ donation wish when they apply for a driver's license. They often receive education about deceased organ donation in order to make an informed choice. The objective of this review was to describe the effectiveness of school-based educational programs on deceased organ donation among adolescents. We reviewed any study of adolescent students receiving a school-based educational program on deceased organ donation. The outcomes were knowledge, attitudes, intent to register a preference toward deceased organ donation, and whether such education fostered family discussions about organ donation. Fifteen studies were summarized from nine countries, of which six were randomized controlled trials. Most educational programs consisted of one or two classroom sessions. The methods employed in five studies received a high-quality rating. Educational programs increased knowledge in 10 studies, and attitudes in five studies, with variable effects on intent to affirmative registration. Seven studies reported success in promoting family discussions. Adolescent classroom education is a promising strategy to improve knowledge about deceased organ donation and appears to increase public support for donation. Subjecting these programs to additional evaluation will clarify their impact on affirmative donor registration and realized donations.

Educational programs play a significant role in deceased organ donation (1). The goal of these programs is to inform the public about organ and tissue donation, the donor registration process (if a registry is available), and to promote discussion with family members and friends about their donation wish (1). Adolescents (aged 12–19) are an important target group for education. Education is a non-controversial solution, and it is essential for adolescents to make an informed decision about organ donation (2).

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Adolescents may also discuss material taught in school with family members (3), who are involved in expressing a donor's wish at the time of an untimely death (4). Finally, in many countries with an active registry, adolescents are prompted to register a wish about deceased organ donation when they apply for a driver's license (5). We conducted this systematic review to assemble the best current evidence on the effectiveness of adolescent school-based educational programs on knowledge, attitudes, and the intent to register a preference for deceased organ donation. We also considered whether such education prompted family discussions about organ donation.

### Methods

We report this systematic review according to the PRISMA statement (6). PRISMA was developed by methodologists, review authors, clinicians, and others and represents an

Abbreviations: CINAHL, Cumulative Index to Nursing and Allied Health Literature; EMBASE, Excerpta Medica Database; ERIC, Education Resources Information Center; GRADE, Grading of Recommendations Assessment, Development and Evaluation; MEDLINE, Medical Literature Analysis and Retrieval System; MeSH, medical subject headings; PRISMA, Preferred Reporting Items for Systematic Reviews and Meta-Analyses.

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evidence-based set of items for reporting in systematic reviews and meta-analyses.

#### Studies eligible for review

A summary of the effectiveness of educational interventions for a given purpose are often too complex to only consider studies that used a randomized controlled trial design (7). A framework for evaluating complex interventions such as educational programs recommends including all quantitative and qualitative research designs in the review (8). For these reasons, we included all research designs in this review. We included any study that evaluated a classroombased educational program on deceased organ donation targeted at adolescents. We also included studies with multiple intervention components as long as at least one component was delivered in school. We excluded any study with educational programs related to stem cell transplantation or blood donation. We excluded studies where <20 students received the educational program because we wanted to examine programs that were tested in an average classroom size setting (although this requirement ultimately did not result in the exclusion of any articles from review) (9). We also excluded studies published in languages other than English.

#### Information sources

We searched the following databases from the date of inception of each database up to June 2011 for eligible studies: MEDLINE (OVID, 1946–2011), EMBASE (OVID, 1980– 2011), CINAHL (EBSCO, 1984–2011), PsycINFO (1806– 2011), and ERIC (1966–2011). We selected the databases and search terms with the help of a medical librarian. The search strategy consisted of MeSH and text words related to organ and tissue donation, educational programs, and adolescents. For example, MeSH terms included: "Tissue and Organs Procurement," "Schools," "Education," and "Adolescent," and text words included "cadaver or deceased donor," "adolescen\*," "teen\*," "educat\*," and "youth\*." We modified the search terms according to the databases used. We conducted citation tracking using SCOPUS and used related articles features in OVID and Google Scholar.

# Study selection

Two reviewers (AL and AR) independently screened titles and abstracts for eligibility. We retrieved full-text articles for any citation considered potentially relevant by at least one reviewer. Both reviewers screened full texts independently for eligibility. We solved any discrepancy among the reviewers by consensus.

# Data abstraction and analysis

Two reviewers (AL and IN) independently abstracted data from the included articles. Data abstraction included study objectives, study design, description of the intervention, participants, and outcomes. Methodological quality was assessed by two reviewers (AL and AR), and discrepancy was solved by consensus. Outcomes of interest were any measured changes in knowledge, attitudes, intention to consent to organ donation, or initiation of discussion with family members or friends after the implementation of the educational intervention. Several studies in this review defined attitudes and the intention to donate as the same concept (10-13). However, for this review, we considered these to be separate outcomes and used the questions described in each study to categorize the results accordingly (described in results section). Based on previous studies, we also classified the study's country by consent policies for organ donation after death (explicit or presumed consent) (14) and whether the country has an active donor registry (15).

### Quality assessment

We used the GRADE framework to guide the assessment of the methodological quality of the studies. We chose GRADE because it is meant to be easy and reliable. Using the GRADE approach, all randomized controlled trials start as high quality and factors such as inconsistency, indirectness, and imprecision affected the quality of evidence (16). Knowledge, attitude, intent to register, and initiation of family discussion may be considered as subjective outcomes. However, for the purpose of this study, we did not consider them as a factor that affected its quality of evidence.

# Results

# Study selection

We screened 1902 articles and assessed 25 fulltext articles for eligibility (Fig. 1). Fifteen studies were eligible for this review (Table 1).

# Description of studies, methods, and participants

Of the 15 studies, six were randomized controlled trials (10, 11, 17–20). Other study designs included a pretest-post-test design that measured changes before and after the implementation of the program with and without a control group that did not receive the educational intervention [no control group (n = 5) (12, 21–24), control group (n = 2) (13, 25)], and a post-test-only design without a control group (n = 2) (26, 27). One pretest-post-test study also incorporated additional qualitative techniques including field notes to extract information from students and observations in a natural classroom setting (24). None of the randomized controlled trials had an active control group receiving a placebo intervention. Controls received the questionnaire prior to the intervention. Most of the studies were conducted in the United States (n = 4), followed by the Netherlands (n = 3), Spain (n = 2)and one study each from Canada, Germany, Italy, India, Poland, and Turkey. Nine of these studies were from countries that have an explicit consent law for deceased organ donation (opt-in), four with a presumed consent law (opt-out), and two were unknown (India and Turkey). Eight of these studies were from countries that have an active registry where participants register

# Classroom education for organ donation

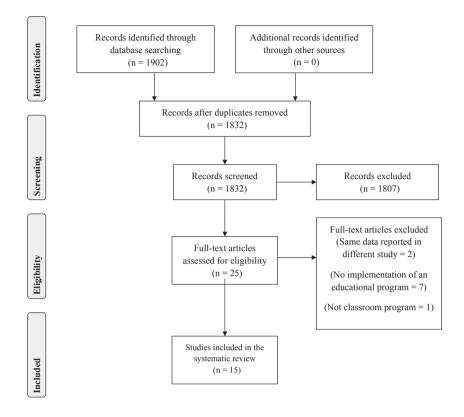


Fig. 1. Study selection.

their intention to donate. Four studies were from countries with no active registry. One study was from a presumed consent country that records objections only (Poland) (26), and another study was from a country with presumed consent that records both objection and affirmative intent to register (Italy) (11).

#### Intervention

The core curriculum of the educational program was similar across all studies. Most educational interventions consisted of one or two classroom sessions about common organ donation myths. When reported, the length of the program ranged from 30 to 120 min. Information and importance of deceased organ donation registration was also provided in three studies from countries that had a donor registry (18-20). The educational intervention was delivered by a variety of personnel including transplant surgeons, kidney transplant recipients, nephrologists, transplant coordinators, and kidney patients waiting for a transplant. Kidney transplant recipients were reported to be volunteer adults (aged 44-64) in one study (19). Otherwise, kidney patients may or may not have been of adolescent age. Components of the programs included videos, group discussions, computerized tailored interventions, and question and answer periods. The educational program in one study focused solely on completing a donor registration form (20). Two studies indicated that their educational programs were informed by a theoretical framework (Bandura's Social Cognitive Theory) (18, 20).

#### Quality assessment of study methods

Five studies were rated as high quality (10, 11, 18-20), six as moderate quality (12, 13, 17, 21, 23, 24), two as low quality (22, 25), and two as very low quality (26, 27). The method of randomization was not described in four of the six trials (17–20). Only two studies used a validated tool for their outcome measures (18, 19). We included all study designs to describe the variability in organ donation curriculum from published educational programs. We found almost complete consensus among the two independent reviewers. We reached similar conclusions for all types of outcomes reported in this review when we compared the results of the five high-quality studies with the other studies of lower quality.

# Knowledge of organ donation

Ten studies examined the impact of an educational program on knowledge or awareness of organ donation and transplantation (10, 12, 13, 17–19, 21, 22, 25, 26) (Table 2a). In all 10

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Table 1. Study characteristics

Title, year, country, consent law, registry	Students	Measurement time-points	Educational program	Overall quality*
Randomized controlled to	rials			
Cárdenas, 2010 (USA) Explicit-Consent Active Registry	96 students education group 91 students control group	Pre- and post-test	40-min program. Presented by ethnically diverse local health workers and organ transplant recipients. Consisted of a 10-min video featuring ethnically diverse teenagers discussing organ donation with a Q&A period	High
Alarcón, 2008 (Spain) Presumed-Consent No active registry	109 students education group 48 students control group	Pre- and post-test	Four-session program. Presented by one of the researchers, a transplant coordinator and a young person on the kidney waiting list. Consisted of a discussion about previous awareness, 10-min video, debate about values and attitudes, discussion about awareness of attitudes in the family setting, talked about results of the discussion at home, explanation about the donation-extraction-transplant process by the researcher and transplant coordinator, testimony <i>in situ</i> of a young undergraduate on the kidney transplant waiting list, Q&A period and group activity	Moderate
Piccoli, 2006 (Italy) Presumed-Consent Active Registry†	Seven schools in control group and seven schools received the education program. 808 (68% response rate) students in the education group answered both pre- and post-test, and 659 (74% response rate) answered both pre- and post-test in control group	Pre- and post-test	Two 2-h sessions. First session was presented to small groups (10–30 students) by a trained nephrology fellow and discussed prevalence, incidence, and causes of kidney diseases in the world, history of dialysis and transplantation, quality of life, allocation criteria, and health globalization. Second session was performed in larger groups (3–8 classes depending on school organization) by a nephrologist supported by nephrology fellows, patients, and experts. Discussed results of the first questionnaires, different aspects of dialysis and transplantation, and Q&A period	High
Reubsaet, 2005 (Netherlands) Explicit-Consent Active Registry	1287 students answered questionnaire in education group 1581 students answered questionnaire in control group	Post-test	Two-part program. First part was a 50-min program consisting of four 5-min video episodes on outcome expectations and misconceptions about organ donation and importance of discussing organ donor registration with family members and group discussion. The video episodes discussed brain death, altruistic benefit of registering as a deceased organ donor, family discussion around organ donation and registration, and the importance of registering an organ donation preference independent of whether one wants to be a donor. Second part consisted of an interactive computer program that provided tailored information about organ donation and registration and an invalid but realistic donor registration form that was meant for practicing	High
Smits, 2005 (Netherlands) Explicit-Consent Active Registry	154 students in education group 165 students in control group	Post-test	45-min lesson presented by five volunteer adult kidney recipients. Consisted of a discussion about organ donation and the Dutch registration system, experiences of a kidney patient, and a Q&A period	High
Reubsaet, 2003 (Netherlands) Explicit-Consent Active Registry	125 students in education group 117 students in control group	Pre- and post-test	Students in the education group were simply invited to practice filling in an invalid but realistic registration form	High
<b>Pre-post-studies</b> Shu, 2011 (Ontario, Canada) Explicit-Consent Active Registry	1832 pretest and 1440 post-test	Pre- and post-test	Consisted of an educational video on organ donation and teachers can select content from 10 curriculum booklets covering personal stories of donor families, transplant recipients, patients on waitlist and scientifically accurate information on organs and tissues to present to class	Moderate
Tokalak, 2006 (Turkey) Unknown No active registry	189 pretest (95% response rate) and 138 post-test (69% response rate)	Pre- and post-test	No description of intervention	Moderate

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Table 1. Continued

Title, year, country, consent law, registry	Students	Measurement time-points	Educational program	Overall quality*
Waldrop, 2004 (USA) Explicit-Consent Active registry	336 students	Pre- and post-test	30-min program. Presented by trained educators and transplant recipients; consisted of a discussion about the need for organs and donation decisions and Q&A period. One week later, students were placed in groups for 15 min to discuss students' experiences regarding their discussion about organ donation with their family	Moderate
Anantachoti, 2001 (USA) Explicit-Consent Active registry	665 students from 16 different classes 553 pretest, 585 post-test and 460 answered 1-month post- test	Pre- and post- test, 1-month delayed post- test questionnaire	60-min program. Presented by trained volunteers (i.e., transplant recipients or members of donor families). Consisted of an overview of organ donation and transplantation, video, and group discussion	Moderate
Weaver, 2000 (USA) Explicit-Consent Active registry	36 students in education group 36 students in control group	Pre- and post-test	40-min program. Presented by transplant surgeon, young ED kidney transplant recipient, and white male heart transplant recipient. Consisted of an overview of medical information and Q&A period	Moderate
Meier, 1999 (Germany) Explicit-Consent No active registry	31 students in education group 36 students in control group	Pre- and post-test	Two 45-min sessions on organ donation and transplantation	Low
Wig, 1999 (India) Unknown Unknown	188 students	Pre- and post-test	Single program delivering information and material on brain death and organ transplantation	Low
Post-test only				., .
Milaniak, 2010 (Poland) Presumed-consent Active registry‡	680 students from 25 schools	Post-test	45-min program. Presented by transplant coordinator, transplant recipients, and donor family; discussed basic facts of organ donation and transplantation, video and group discussion	Very low
Mate, 2005 (Spain) Presumed-consent No active registry	~161 classes	Post-test	Single program. Presented by health professionals; discussed the need of organ donation, current transplantable organs and tissues, daily activity in hospital, who may become a donor and recipient, concept of brain death and difference from cardiac arrest death, difference between coma and brain death and group discussion	Very low

Q&A: Question and Answer.

\*As assessed by the GRADE system, see "Methods" section. The grades range from "very low" to "high" guality.

\*Records both an objection and intent to donate.

‡Records an objection to donate.

studies, there was a significant increase in knowledge or awareness after the educational program. A questionnaire was used in all studies to assess knowledge, which consisted of 4–26 multiple-choice questions (18, 21). Topics covered in the questions included which organs are eligible for transplant, transplant waitlist composition, deceased organ donor registration, brain death concepts, and popular myths around organ donation. One study did not specify the questions that were used (25).

#### Attitudes toward organ donation

Five studies measured attitudes toward organ donation, which in each study was carried out differently (18, 19, 21, 23, 26) (Table 2b). In all five studies, there was a significant increase in attitudes after the educational program. One study measured expectations of social outcomes (e.g., "My friends find it important that I register my organ donation preference.") and expectations of negative outcomes (e.g., "By registration as an organ donor, I run the risk that my organs may be traded after my death.") concerning organ donation and registration (18). Another study measured five factors related to attitude: anxiety, self-control over the decision to donate, and expectations of negative, positive and social outcomes (19). These two studies used a questionnaire that had demonstrated good psychometric qualities (18) or was informed by previous research (18, 19). The other three studies measured attitude using a Likert scale and asked participants subjective questions (e.g., How much do you support organ donation?) (21, 23, 26).

Intention and willingness to become an organ donor

Intention or willingness to become an organ donor was measured in several different ways

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#### Table 2. Outcomes measured

Study	Control Group	Findings
(a) Knowledge		
Cárdenas, 2010	Yes	When responses to all 16 questions were aggregated, the scores on the post-test were significantly higher in the education group than in the control group ( $p < 0.001$ ). For 12 of 16 statements, the increase in the percentage of students with correct responses on the post-test was significantly greater in the education group than in the
Milaniak, 2010	No	control group After the program, more than 80% and 60% of the students correctly responded to seven of 10, and two of 10 questions on
Alarcón, 2008	Yes	transplantation, respectively The education group reported having higher levels of information compared to the control group. In the education group, the levels of information reported as none, low, high, and very high were 0%, 3%, 73%, and 24%, compared to 19%, 50%, 29%, and 2% in the control group. Authors did not report any comparison between pretest and post-test between the groups
Tokalak, 2006	No	After the program, there was an increase in students correctly identifying the concept of brain death (66–92%; $p < 0.001$ ), the definition of transplantation (68–91%; $p < 0.001$ ), and the major organs and tissues that can currently be transplanted ( $p < 0.001$ )
Smits, 2005	Yes	The mean score was higher in education group for both students at the higher general educational level and university preparation level than those of the control group (7.9, 8.9 of 14, respectively, compared to 6.6, 6.2). Authors concluded that education group reported more knowledge than the control group ( $p < 0.001$ )
Reubsaet, 2005	Yes	The education group answered on average four of 26 knowledge items on organ donation and registration more correctly compared to the control group ( $p < 0.001$ )
Anantachoti, 2001 Weaver, 2000	No Yes	After the educational program, the mean knowledge score of the study group improved by 0.2 of four ( $p < 0.01$ ) The education group knowledge scores increased by 18% compared to 5% for the control group ( $p = 0.00$ ). Greatest increase in students learning that Asians wait longer for kidney transplants than Caucasians (50% compared to 17% increase in control group) and students learning that the type of diseases that lead to the need for transplant are not unusual and rare (19% compared to 0% increase in control group)
Wig, 1999	No	After the program, there was an increase in students correctly identifying major organs and tissues that can currently be transplanted and the concept of brain dead being possible organ donors (66–99%)
Meier, 1999	Yes	The authors simply reported that the education group's knowledge increased as a result of the educational program ( $p < 0.001$ )
<i>(b) Attitude</i> Shu, 2011	No	The exact values are not reported, but eight selected questions from the attitudinal surveys showed significant changes ( $p = .00625$ ). The authors reported an increase in students who strongly agreed that they have an obligation to take care of others through organ and tissue donation (19–27%) and decrease in students who strongly disagreed with the misconception that doctors and nurses would not try as hard to save the student if they knew they had agree to organ and tissue donation (31–43%)
Milaniak, 2010	No	After the educational program, approximately 97% of students strongly believed the statement, "Organ transplantation is an efficacious method of treatment to save other people's lives"
Smits, 2005	Yes	The education group experienced significantly less expectations about negative outcomes ( $p < 0.05$ ), more expectations of positive outcomes ( $p < 0.05$ ), and more self-control over the decision to donate ( $p < 0.001$ ) compared to the control group
Reubsaet, 2005	Yes	The education group experienced less expectations of negative outcomes concerning organ donation and registration ( $p < 0.001$ ) and higher expectations of social outcomes regarding organ donation and registration ( $p < 0.001$ ). Students in the education group were also significantly more confident about being able to complete the registration procedure ( $p < 0.001$ )
Anantachoti, 2001	No	After the educational program, students improved significantly on eight of nine attitude items ( $p < 0.001$ ) and mean attitude scores improved by 1.74 of nine ( $p < 0.01$ ). The largest improvement in attitude score was for "Organ recipients can return to a normal and healthy life" and least improvement in "The subject of organ donation grosses me out."
(c) Intention or willi	ingness to	
Cárdenas, 2010	Yes	In the education group, 31% changed the students' willingness to donate in a positive direction, 14% in a negative direction, and 55% remained unchanged compared to the control group in which only 7% changed their opinions in a positive direction, 8% in a negative direction, and 85% remained unchanged. The odds that the students in the education group would have a positive change in willingness to donate compared to control group was 7.14
Milaniak, 2010	No	After the program, more than 90% of students wanted to sign a donor card (only 8% of students carried a donor card before the program). 74% agreed to sign a donor card with their identification card. Over 80% of students were ready to agree to give their organs after death
Alarcón, 2008	Yes	84% of the students in the education group stated that they would donate their own organs compared to 56% of the control group. 77% stated they would consent to donating organs from relatives compared to 50% of the control group.
Piccoli, 2006	Yes	In the education group, the program increased the students' willingness to become a deceased donor significantly (from 32% to $43\%$ ), while negative answers decreased (from 34% to $16\%$ ) (p < 0.001). There was no significant change in the control group
Tokalak, 2006	No	After the program, there were an increase in willingness to donate organs after death (from 25% to 38%; $p < 0.001$ ), decrease in opposition to donation (from 14% to 7%; $p < 0.001$ ), and increase in approval for organ donation from a brain dead relative (from 56% to 69%; no reported p-value)
Reubsaet, 2005	Yes	The education group had significantly higher intention to register their organ donation preference and more often intended to register as a deceased organ donor compared to the control group ( $p < 0.001$ )

#### Table 2. Continued

Study	Control Group	Findings
Smits, 2005	Yes	The education group was significantly more willing to fill in the registration form compared to the control group ( $p < 0.001$ ). The education group and control group significantly differed in organ donation choice ( $p < 0.05$ ). Although not significant, the education group was more willing to register as deceased organ donors than the control group (51% compared to 43%). However, a larger proportion of students in the education group also did not want to donate organs after death compared to the control group (28% compared to 22%). The students from the control group were more likely not to send form back and leave the decision to others (36% compared to 12%). The authors concluded that the lesson did not lead to any substantial increase in number of student intending to register as potential organ donors
Reubsaet, 2003	Yes	The education group's intention to register organ donation preferences was significantly higher compared to the control group. However, the program did not result in a higher willingness to register as a potential deceased organ donor
Weaver, 2000	Yes	The responses of the education group as a whole were not significantly different from those of the control group. However, subgroup analysis revealed that opinions of becoming an organ donor among the ethnic students were more positive than at baseline (net increase of 7% toward a positive opinion of being an organ donor). There was a positive increase in opinions toward becoming an organ donor in 18% of ethnic students compared to no increase among white students ( $p = 0.04$ )
Meier, 1999	Yes	The education group's willingness to donate increased ( $p < 0.001$ ). However, improvements in willingness to donate could not be replicated in the control group after they received the program
(d) Family discussio	n	
Milaniak, 2010	No	After the program, 37% males and 46% females reported they had discussed organ donation and shared their decision with family
Alarcón, 2008	Yes	79% of the education group stated they had discussed organ donation compared to 21% in control group
Piccoli, 2006	Yes	After the program, 58% of the students discussed transplant issues with their families
Mate, 2005	No	After the program, 60.8% talked with friends and 68.8% at home
Waldrop, 2004	No	Of the students that responded to the study, 61% of the middle school and 58% of the high school students indicated that it went "ok," and a smaller percentage (24% middle and 38% high school) of responses indicated that it went "very well"
Anantachoti, 2001	No	After the program, there was an increase in students considering discussing organ donation with families (86–91%; $p < 0.001$ ). The 1-month delayed post-test questionnaire revealed that 70% of the students had a discussion about organ donation with family or friends
Meier, 1999	Yes	It was not clear that family discussion improved. The study reported that after the education group and the control group received the program, both groups communicated more about organ donation and transplantation ( $p < 0.001$ )

across 10 studies (10-13, 17-20, 25, 26) (Table 2c). Overall, the programs had variable and inconsistent effects on the intent to affirmative registration. Four studies measured the student's intention to register their preference toward organ donation in an organ donor registry or through a donor card (either for or against donation; for example, "Do you intend to fill in or send back the registration form?") (18–20, 26), and all but one study measured the student's willingness to become a deceased organ donor (11) (e.g., "Would you donate your organs to another person after your death?"). This study used a hypothetical situation as to whether the student would consent to donating a deceased family member's organs if the student was unaware of the wishes of the deceased (11). In this study, the educational program significantly decreased the number of students who objected to donating their deceased family member's organs. One study found that the educational program did not significantly increase the intention to donate for the entire student body, but there was a significant increase in ethnic students (13). Another study found that the educational program did increase the student's intention to register their choice, although a large proportion of students indicated they would register against donation (19). One study that focused simply on filling out an invalid but realistic registration form increased the students' intention to fill out the form but did not increase the number of students intending to register as deceased organ donors (20). However, a larger study using the same exercise combined with video, group discussion, and interactive computer program found significant higher measures of intent to register and affirmative registration as a deceased organ donor in the education group compared to control group (18). Another study noted that the educational program initially influenced the students' willingness to donate in the experimental group but could not achieve a similar effect after the educational program was delivered to the control group (25).

# Family discussion

Seven studies described the effect of the educational program on promoting organ donation discussions with family members (11, 17, 21, 24–27) (Table 2d). All six studies reported success in this regard. One study using qualitative techniques reported that "getting started" was the most difficult component of discussing organ donation with family (24).

# Discussion

In this systematic review summarizing 15 studies from nine countries, adolescent classroom education appeared increased knowledge (10 of 10 studies) and attitudes (five of five studies) with variable effects on intent to affirmative registration. Six studies reported success in promoting family discussions. While a willingness to become a donor is expected to be a positive predictor of actual consent for organ donation, no study measured any change in actual donation registration, donor consent rates, or realized donations.

Several caveats about the primary studies should be noted when interpreting this review. The educational programs and outcome measures described in various studies were quite different, making a direct comparison of the results difficult. Furthermore, all of the higherquality studies were from the United States or European nations, limiting the generalizability of this review's findings to all educational systems and cultural contexts. A majority of the studies were conducted in explicit consent ("opt-in") countries for deceased organ donation with active intent to donate registries. Many studies did not provide sufficient information about the curriculum of their educational component and did not expand on the specific content presented. This prevented us from identifying which elements of the educational program were associated with effectiveness. There were no studies comparing different types of educators, content, or culture-specific interventions with standardized interventions. A major consideration regarding the curriculum was whether the purpose of the educational program was to foster pro-transplant opinions in students or to simply provide information so that students could make an informed decision about organ donation. Only two studies explicitly mentioned that the educational intervention was designed to inform rather than convince (10, 13). Further, our conclusion on the efficacy of classroom education is limited given that no studies compared donor education class with interventions that focus on positive social behaviors (e.g., discussing what it means to be a good citizen). Given all these caveats, there are limitations that can be drawn from the literature. The value of our review is to highlight these issues so that they can be addressed in future improved studies.

After completing this review, we make the following recommendations about adolescent organ donation educational programs, recognizing there is variable empiric evidence to support some statements. First, these educational programs appear effective at increasing adolescent's knowledge, attitude, and initiation of family discussion on organ donation. Thus, their use should be encouraged and supported for those reasons. Second, implicit in need to resource educational programs is the growing unmet demand for organs (28). Educators should always respect individual choice but should not be shy to reveal that the need for organs is great, with preventable deaths on transplant waiting lists. In other words, these programs are fostering the charitable nature of adolescents, who are future adult members of society. Establishing a more consistent benefit of these programs on the willingness to donate is an important goal (which in the literature was variable). However, advocacy does need to be presented with due care. For example, one study provided donor cards at the end of their educational intervention (26), a component that results in ethical discussion to avoid perceptions of indoctrination or a student being marginalized for their choice against donation. Third, it is important to consider the amount of classroom time required. In terms of the length of such a session. 1 h appears to be sufficient based on the general length of sessions from the reviewed studies. Finally, although not a primary objective of this review, we found that students commonly had misconceptions regarding brain death (12, 22) and the composition of the waitlist and the organ allocation system (10, 13). Therefore, it remains prudent that programs include these topics in their curriculum.

Another research focus is to move beyond the measurement of intent to register for organ donation, to actual affirmative registration values and deceased organ donor consent rates. It is possible that the students in the reviewed studies responded according to the desired responses of the researchers, which would not translate into actual change. There is also inertia, with a gap between the willingness to donate and attitude toward donation, and actually registering to become a donor (29, 30). To illustrate this point, one recent survey found that 90% of the survey population was willing to consider donation but this did not correspond to having a signed donor card (29). However, it is important to note that actual affirmative registration values would be of interest and applicable to countries with an explicit consent law and an active intention to donate registry. Finally, any future trials should use validated scales and a comparison group of students who do not receive the educational program (at least initially) as done in some but not all prior studies.

However, it is important to acknowledge several challenges to conducting this type of research in classrooms. These challenges include the need for parental permission, separate administrative approvals for this research, and competing with other important health education initiatives (e.g., drug prevention) in schools with limited time. Advocacy to school boards for the importance of organ donation education in the adolescent population may overcome these barriers.

Our review has a number of strengths. We screened almost 2000 articles to identify studies relevant for this review. We searched for relevant studies using robust methods in multiple bibliographic databases. Article screening was performed independently and in duplicate, to avoid subjectivity in this task. We assessed the methodological quality of included studies using a valid scale. However, there are some limitations to our review that bear mention. The exclusion of non-English studies may have introduced some bias (31), although this is controversial (32). Readers may need to consider the contextual utility of our results. As we wanted to include complete evaluations that had been subject to peer review, we did not search non-published sources. Nonetheless, readers may want to consider local publications for similar studies. Finally, there may be a positive publication bias as many of the evaluators of the education programs may have also been invested in their development and implementation.

In conclusion, adolescent classroom education is a promising strategy to improve public support for deceased organ donation. Subjecting these programs to additional evaluation, including knowledge of the impact on affirmative donor registration and realized donations, will guide their optimal design and use.

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#### Authors' contributions

All authors (AHL, AMR, IFN, and AXG) conceived of the study. AHL and AXR independently reviewed the full texts of all articles. All authors (AHL, AMR, IFN, and AXG) had full access to data and can take responsibility for the integrity of the data and the accuracy of the data analysis. AHL and AXG drafted the manuscript. All authors revised the manuscript.

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#### References

- 1. DEJONG W, DRACHMAN J, GORTMAKER SL. Options for increasing organ donation: the potential role of financial incentives, standardized hospital procedures, and public education to promote family discussion. Milbank Q 1995: 73: 463–479.
- CANTAROVICH F, CANTAROVICH D. Education and organ donation: 'the unfinished symphony'. Transpl Int 2012: 25: e53–e54.
- 3. CANTAROVICH F. The role of education in increasing organ donation. Ann Transplant 2004: 9: 39–42.
- ROSENBLUM AM, HORVAT LD, SIMINOFF LA, PRAKASH V, BEITEL J, GARG AX. The authority of next-of-kin in explicit and presumed consent systems for deceased organ donation: An analysis of 54 nations. Nephrol Dial Transplant 2012: 27: 2533–2546.
- THORNTON JD, WONG KA, CARDENAS V, CURTIS JR, SPIGNER C, ALLEN MD. Ethnic and gender differences in willingness among high school students to donate organs. J Adolesc Health 2006: 39: 266–274.
- MOHER D, LIBERATI A, TETZLAFF J, ALTMAN DG. Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. PLoS Med 2009: 6: e1000097.
- GILBODY S, WHITTY P, GRIMSHAW J, THOMAS R. Educational and organizational interventions to improve the management of depression in primary care: A systematic review. JAMA 2003: 289: 3145–3151.
- 8. CAMPBELL M, FITZPATRICK R, HAINES A, et al. Framework for design and evaluation of complex interventions to improve health. BMJ 2000: 321: 694–696.
- 9. OECD. How Many Students Are in Each Classroom? In Education at a Glance 2012: Highlights: OECD Publishing, 2012.
- CARDENAS V, THORNTON JD, WONG KA, SPIGNER C, ALLEN MD. Effects of classroom education on knowledge and attitudes regarding organ donation in ethnically diverse urban high schools. Clin Transplant 2010: 24: 784–793.
- 11. PICCOLI GB, SORAGNA G, PUTAGGIO S, et al. Efficacy of an educational programme for secondary school students on opinions on renal transplantation and organ donation: A randomized controlled trial. Nephrol Dial Transplant 2006: 21: 499–509.
- TOKALAK I, KUT A, MORAY G, et al. Knowledge and attitudes of high school students related to organ donation and transplantation: A cross-sectional survey in Turkey. Saudi J Kidney Dis Transpl 2006: 17: 491–496.
- WEAVER M, SPIGNER C, PINEDA M, RABUN KG, ALLEN MD. Knowledge and opinions about organ donation among urban high school students: Pilot test of a health education program. Clin Transplant 2000: 14: 292–303.
- HORVAT LD, CUERDEN MS, KIM SJ, KOVAL JJ, YOUNG A, GARG AX. Informing the debate: Rates of kidney transplantation in nations with presumed consent. Ann Intern Med 2010: 153: 641–649.
- ROSENBLUM AM, LI AH, ROELS L, et al. Worldwide variability in deceased organ donation registries. Transpl Int 2012: 25: 801–811.
- GUYATT GH, OXMAN AD, KUNZ R, VIST GE, FALCK-YTTER Y, SCHÜNEMANN HJ. What is "quality of evidence" and why is it important to clinicians? BMJ 2008: 336: 995–998.
- 17. ALARCON R, BLANCA MJ, FRUTOS MA. Assessment of an educational program for adolescents about organ donation and transplantation. Transpl Proc 2008: 40: 2877–2878.
- 18. REUBSAET A, BRUG J, NIJKAMP MD, CANDEL MJ, VAN HOOFF JP, VAN DEN BORNE HW. The impact of an organ donation

registration information program for high school students in the Netherlands. Soc Sci Med 2005: 60: 1479–1486.

- 19. SMITS M, VAN DEN BORNE B, DIJKER AJ, RYCKMAN RM. Increasing Dutch adolescents' willingness to register their organ donation preference: The effectiveness of an education programme delivered by kidney transplantation patients. Eur J Pub Health 2006: 16: 106–110.
- REUBSAET A, BRUG J, DE VET E, VAN DEN BORNE B. The effects of practicing registration of organ donation preference on selfefficacy and registration intention: An enactive mastery experience. Psychol Health 2003: 18: 585–594.
- ANANTACHOTI P, GROSS CR, GUNDERSON S. Promoting organ donation among high school students: An educational intervention. Prog Transplant 2001: 11: 201–207.
- 22. WIG N, AGGARWAL P, KAILASH S, HANDA R, WALI JP. Awareness of brain death and organ transplantation among high school children. Indian J Pediatr 1999: 66: 189–192.
- SHU J, FOK T, MUSSEN L, et al. Impact of the educational resource one life... many gifts on attitudes of secondary school students towards organ and tissue donation and transplantation. Transpl Proc 2011: 43: 1418–1420.
- 24. WALDROP DP, TAMBURLIN JA, THOMPSON SJ, SIMON M. Life and death decisions: Using school-based health education to facilitate family discussion about organ and tissue donation. Death Stud 2004: 28: 643–657.

- MEIER D, SCHULZ KH, KUHLENCORDT R, CLAUSEN C, ROGIERS X. Effects of an educational segment concerning organ donation and transplantation. Transpl Proc 2000: 32: 62–63.
- MILANIAK I, PRZYBYLOWSKI P, WIERZBICKI K, SADOWSKI J. Organ transplant education: The way to form altruistic behaviors among secondary school students toward organ donation. Transpl Proc 2010: 42: 130–133.
- 27. MATE G, MORILLA T, COLON LL, et al. Information program about organ and tissue transplant-donation process at the secondary schools in the province of Girona (Spain). Transpl Proc 2005: 37: 3641–3642.
- ABOUNA GM. Organ shortage crisis: Problems and possible solutions. Transpl Proc 2008: 40: 34–38.
- 29. LEE E, MIDODIZI W, GOURISHANKAR S. Attitudes and opinions on organ donation: An opportunity to educate in a Canadian city. Clin Transplant 2010: 24: E223–E229.
- HEALY G, SHARMA K, HEALY DG. Transplantation, multiorgan donation & presumed consent: A 3 year survey of university students. Ir Med J 2009: 102: 297–298.
- EGGER M, ZELLWEGER-ZAHNER T, SCHNEIDER M, JUNKER C, LENG-ELER C, ANTES G. Language bias in randomised controlled trials published in English and German. Lancet 1997: 350: 326–329.
- MOHER D, PHAM B, KLASSEN TP, et al. What contributions do languages other than English make on the results of meta-analyses? J Clin Epidemiol 2000: 53: 964–972.