Public Awareness and Attitudes to Living Organ Donation: Systematic Review and Integrative Synthesis

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Public Awareness and Attitudes to Living Organ Donation: Systematic Review and Integrative Synthesis

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Background. The deceased-donor organ shortage has driven widespread adoption of living-donor transplantation. Yet, public views on living donation are not well understood. This study aims to synthesize studies on public awareness and attitudes toward living organ donation.

Methods. Electronic databases and reference lists were searched to September 2012. Summary estimates from survey data were obtained by random effects meta-analysis. Qualitative descriptive synthesis of each study was performed.

Results. Forty-seven studies involving 34,610 respondents were included. The proportion of respondents aware of living organ donation was 76.7% (4 studies, n=3248; 95% confidence interval, 46.2%–97.0%; I^2=99.7%). The majority were in favor of living directed donation (85.5% (11 studies, n=15,836; 95% confidence interval, 81.6%–89.6%; I^2=98%), with recipient and community benefit as the rationale provided. However, barriers included fear of surgical and health risks, lack of knowledge, respect for cultural norms, financial loss, distrust in hospitals, and avoiding recipient indebtedness. The public voiced concern about possible risks or an obligatory pressure exerted on the donor. Many supported reimbursement for out-of-pocket expenses, paid leave, wait-listing priority, health insurance, and donor acknowledgment. There was strong opposition to financial incentives, which they believed risked exploitation and inequity and diminished voluntary altruistic donation.

Conclusions. The public is generally supportive of living donation and articulated important equity and ethical considerations for protecting the health and safety of living donors. This supports increased public engagement and strengthening of a shared view among professionals and the public in living donation practice and policy.

Keywords: Organ donation, Live donor, Public policy, Ethics.

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The scarcity of suitable organs for transplantation has driven widespread acceptance of living-donor transplantation (*1–3*). Although living-donor transplantation offers superior survival and quality of life for recipients compared with deceased donation, donors face the risks of surgical complications, potential physical and psychosocial harms, and death (*4–6*). In the United States, the donor mortality rate due to surgical complications is 0.03% (*7*). The reported rate is ≤0.5% for postsurgical complications requiring reoperation and ≤1.0% for complications not requiring reoperation (*8*). Donor deaths and a variety of adverse outcomes have been reported in the medical literature and publicized in mass media (*9–11*), raising concerns among both the professional and general community about donor health and safety (*2*).

Intrinsic to the process is that healthy individuals must be willing to accept risks of potential harms of donating an organ, usually kidney or liver, including uncertain long-term consequences. Despite this, the general public is largely supportive of living donation (*12–14*). The importance of public involvement in decision-making in policy

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A.T. designed the study, conducted the systematic review and synthesis, and drafted the article. J.R.C. participated in the design of the study and review, provided the content expertise, and reviewed the article. G.W. participated in the design of the study, collected and analyzed the data, and contributed to the writing of the article. M.A.J. contributed to the design of the study and writing of the article. J.C.C. participated in the design of the study and data analysis and contributed to the writing of the article. A.T. is the guarantor.

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development to promote public confidence has been increasingly recognized (*15, 16*). Yet, it is unclear if current practices and policies for living donation are cognizant of public preferences.

Lack of public input or insufficient understanding of public preferences could lead to potential controversy in the formulation of policy regarding living-donor transplantation. The public is a stakeholder group that, importantly, does not have a direct personal or professional vested interest in increasing donation rates. Equity and ethical standards are important underpinnings of organ donation, to which the public can contribute useful and considerable insight. This study aims to review and synthesize published studies that have assessed public awareness of and attitudes to living organ donation to inform healthcare service provision and policy regarding living organ donation.

RESULTS

Literature Search and Study Characteristics

Our search yielded 5079 articles, and 47 involving 34,610 participants were included (Fig. 1). The characteristics of the studies are provided in Table S1 (see **SDC,** http://links.lww.com/TP/A814). Forty (85%) studies reported the conduct of surveys and 7 (14%) used qualitative methods (focus groups and interviews) to collect data. Twenty-six (26%) studies included solid organ donation broadly, 15 (32%) focused on kidney donation, 4 (9%) on liver donation, and 1 (2%) on both kidney and liver donation. In 9 (19%) studies, participants of a specific religion or ethnicity were recruited. The studies were conducted in 20 countries.

Appraisal of Study Reporting

Of the 40 survey studies, the comprehensiveness of reporting was variable with studies reporting on 2 to 11 of the 16 items (Table 1). Thirty-seven (93%) studies specified their sampling strategy and mode of survey delivery and provided a description of the survey, and 10 (25%) reported whether surveys were anonymously completed. Response rates were reported in 26 (65%) studies. Of the 7 qualitative studies, 6 (86%) stated the questions or topics used to collect data, reported the use of audio recording, and provided quotations to support their findings. Four (57%) specified that theoretical saturation was reached, that is, little or no new data were arising from subsequent interviews for focus groups. Two (29%) reported the use of software to facilitate data analysis.

Integrative Synthesis

Quantitative and qualitative findings were organized into nine themes: knowledge about living donation, support for and willingness to be a living donor, perceived benefits of living donation, concerns and barriers to living donation, acceptance of living-donor organs, solicitation of living donors, donor autonomy, altruistic anonymous donation, and compensation and incentives. Under each thematic heading, summary estimates are reported, where available, followed by qualitative descriptive findings.

Knowledge About Living Donation

There was wide variation between studies in the proportion of respondents who reported they were aware that living organ donation was possible (*17–23*). The summary

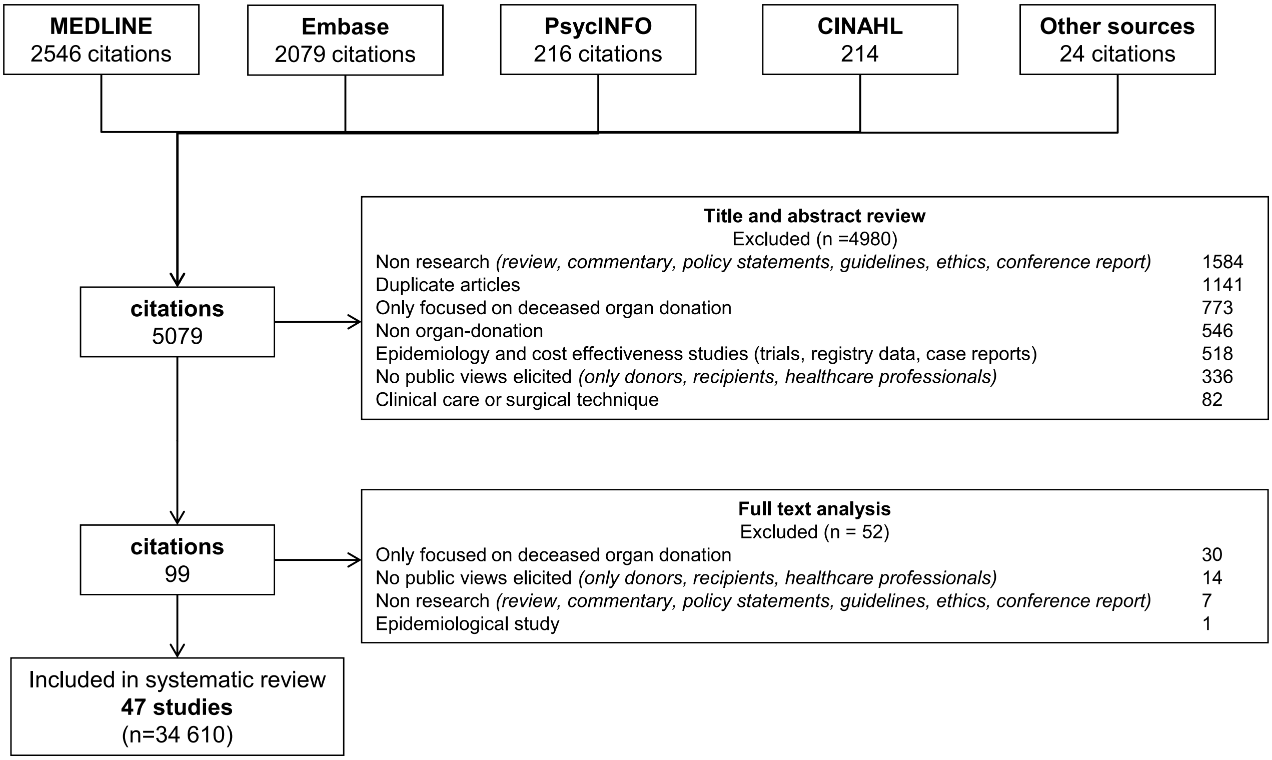

FIGURE 1. Search results.

TABLE 1. Comprehensiveness of reporting in survey studies

Participant characteristics	References	Number of studies
Sampling strategy (e.g., random and comprehensive)	(*12–14, 18–24, 26–47, 52, 54, 56–58, 80*)	37
Exclusion criteria	(*18, 20, 27, 30, 33, 36, 39, 43, 52*)	9
Response rate	(*13, 14, 18, 19, 22–26, 29–31, 33–35, 37–41, 45, 52, 56–58, 80*)	26
Characteristics of the sample	(*13, 14, 17–24, 27, 29–46, 52, 54, 56, 58, 80*)	34
Characteristics of refusals	(*18*)	1
Survey administration		
Method of approach or invitation	(*13, 18, 21, 22, 24, 27, 28, 30, 31, 33, 35–41, 43–46, 52, 56, 58, 80*)	25
Mode of delivery	(*12–14, 18, 19, 21–41, 43–47, 52, 54, 56–58, 80*)	37
Incentive	(*19, 36, 37, 41, 43*)	5
Follow-up reminder	—	0
Anonymity	(*13, 14, 23, 26–30, 34, 43*)	10
Survey design		
Piloting or validation	(*14, 18, 23, 26, 28, 29, 34, 36, 39, 41*)	10
Description of survey development	(*13, 18, 19, 22, 24, 29, 30, 34, 37, 39–41, 43, 45, 47*)	15
Survey tool, ranking exercises described or provided	(*12–14, 17–19, 21–24, 26, 27, 29–47, 52, 54, 56–58, 80*)	37
Data analysis		
Description of statistical analysis	(*13, 14, 17–24, 26–31, 33–41, 43–47, 52, 54, 56, 57, 80*)	35

estimate of the proportion of respondents aware about the possibility of living organ donation was 76.7% (4 studies, n=3248; 95% confidence interval [CI], 46.2%–97.0%; I^2= 99.7%) (see **Table S2, SDC**, http://links.lww.com/TP/A814). One study conducted in South Africa found that a higher proportion knew kidney donation was possible (96%) compared with liver donation (62%) (*23*).

Support for and Willingness to Be a Live Donor

Most studies assessed associations between sociodemographic and attitudinal factors with public support for live donation and willingness to be a live donor. The majority were in favor of directed living donation (*12–14, 24–31*). The summary estimate of the proportion of respondents in favor of living directed donation for liver, kidney, or other organs was 85.5% (11 studies, n=15,836; 95% CI, 81.6%–89.6%; I^2=98%). Subgroup analyses were conducted by organ types to explore the possible sources of heterogeneity. The summary estimate of the proportion of respondents in favor of living-directed kidney donation was 90% (5 studies, n=6617; 95% CI, 88%–92%). The I^2 was 82%, indicating unexplained heterogeneity between studies (Fig. 2; see **Table S3, SDC**, http://links.lww.com/TP/A814). In addition, 80.7% (3 studies, n=5543; 95% CI, 73.8%–86.8%; I^2=96.4%) of respondents were in favor of living-directed liver donation. Respondents in four studies (*13,*

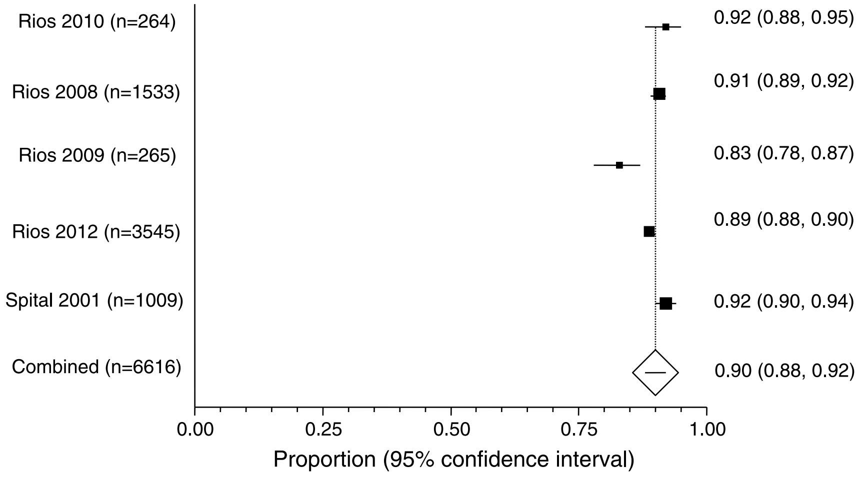

FIGURE 2. Summary estimates for the proportion of respondents in principle supportive of living directed donation (I^2=82.0%).

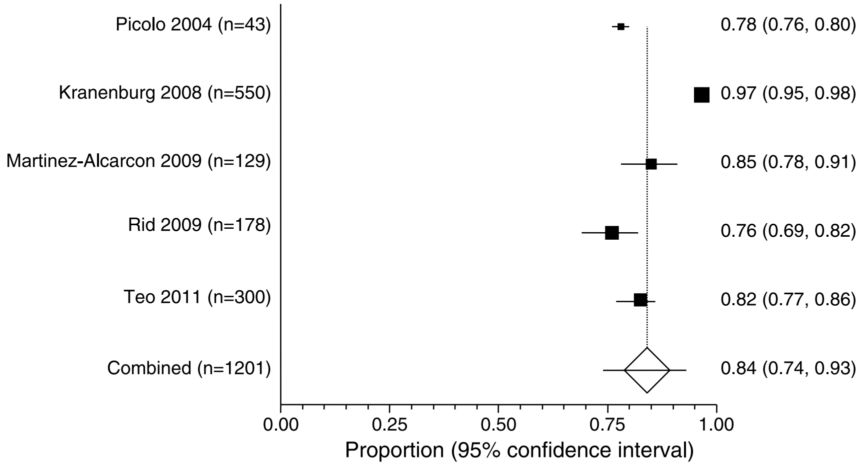

FIGURE 3. Summary estimates for the proportion of respondents who would consider donating a kidney to a known recipient (I^2=97.4%).

27–29) conducted in Spain indicated less support for unrelated or nondirected donation, whereas two U.S. studies found that the public were mostly supportive of nondirected donation (*12, 31*) (see **Table S4, SDC,** http://links.lww.com/TP/A814).

Public willingness to be a living donor to a known (related and/or unrelated) and unknown recipient was assessed in 24 studies (*12, 18, 20, 21, 24, 25, 30–46*). In general, participants were more willing to be a living donor to a known than an unknown recipient. The proportion of participants willing to be a living kidney donor to a known recipient was 84.4% (5 studies, n=2833; 95% CI, 73.8%–92.8%; I^2=97.4%) (Fig. 3). However, only 33% (4 studies, n=3736; 95% CI, 22.8%–44.5%; I^2=97.6%) would consider living donation to an unknown recipient (Fig. 4). A higher proportion would be willing to donate to a child (>90%) than to spousal, parent, or sibling recipients (*25, 39*).

Although the proportion of participants willing to donate to an unrelated or unknown recipient was discernibly less (*24, 25, 31, 32, 37, 38, 43, 47*), one study conducted in The Netherlands (2008) (*36*) found that 83.4% would consider donating to an unknown recipient. Paired kidney exchange, in which donor organs are exchanged between two donor–recipient pairs due to medical necessity, was generally judged an acceptable reciprocity.

Perceived Benefits of Living Donation

Living donation was perceived to result in a benefit to the recipient and to the community(*30, 48–51*). The public believed donors would gain a sense of reward and satisfaction. In one study, donation was considered an inherent responsibility if the potential recipient was a family member (*50*).

Concerns and Barriers to Living Donation

Several barriers and concerns were expressed, including fears about surgical and health risks (*13, 18, 26, 39, 48, 52*), lack of knowledge about organ donation (*13, 48*), respect for cultural or religious norms (e.g., to obey "family's wishes" (*30*) and avoid "damage" to the body (*53*)), financial

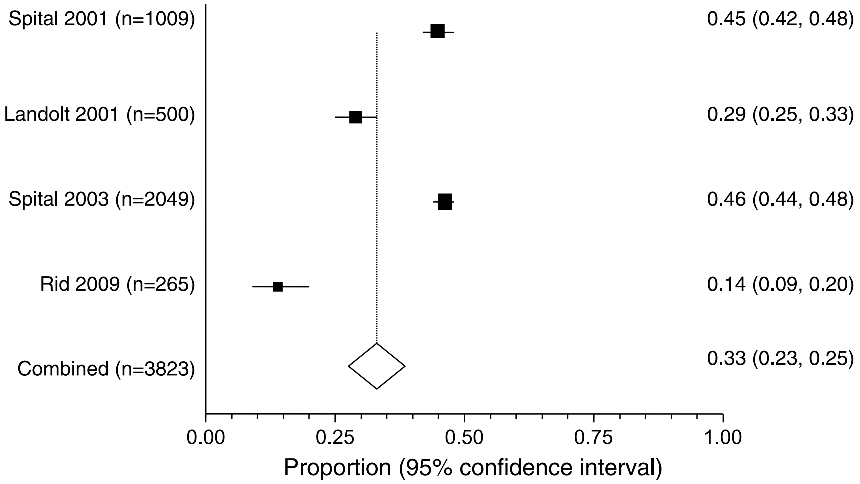

FIGURE 4. Summary estimates for the proportion of respondents who would consider donating a kidney to an unknown recipient (I^2=97.6%).

loss (*39, 52*), distrust in hospitals (*33*), and avoiding recipient indebtedness (*44*). Apprehension about living donation was mainly due to a perceived potential detriment to donor health. There was concern about the possibility of surgical risks, side effects, appearance of the scar, and the donor requiring a transplant in the future. In one study, the median chance of survival that respondents would accept before becoming a living liver donor for a loved one was 79% (interquartile range, 51%–95%) (*54*). Another study found that respondents would be willing to accept added risk if donating to their child (*31*). In one study, respondents were presented with the following statement "in about 1 in 200 cases the operation can lead to the death of the donor," and 42% believed this risk was acceptable if donating to family member and 14% believed this risk level was acceptable when donating to a friend (*25*).

Respondents indicated that the median recipient survival they would accept before consenting to living liver donation was 55% (interquartile range, 49%–80%) (*54*) Also, there was greater willingness to donate to younger parents (50–75 years) versus older parents (>75 years), to recipients in a potentially life-threatening situation, to children, and to recipients whose liver disease was caused by cancer versus alcohol consumption (*35*).

In a U.S. study restricted to Hispanics, some felt they could not be a living donor because it was against their family's wishes or religious stance (*30*). Similarly, in a study conducted among Chinese Canadians, donation was viewed as a "disgrace to the parents." (*53*) Out-of-pocket expenses and potential job loss could also dissuade donation (*33, 39*) as well as distrust in hospitals (*33*). In one study, concern about recipient emotional indebtedness was expressed, "[recipients will be unable to] do enough in return…and will feel guilty for the rest of their lives without any prospect of settling their account (*55*)."

Acceptance of Living-Donor Organs

Willingness to accept a living-donor organ was considered in terms of medical urgency, waiting time, and recipient and donor outcomes. One study found that willingness to accept a graft was largely premised on whether there was a "life-threatening need," or if the "living donation would shorten the waiting period," or if the "results of living donation would be better than that for cadaveric donation" (*35*). They would be reluctant to accept an organ if there was "a significant risk for the donor" (*35*) or would "cause long-term problems for the donor" (*42*).

Solicitation of Living Donors

Three studies examined whether respondents would solicit donors from among their family members (*34, 45, 48*). In one study, 35% of participants would be unwilling to request organs from their friends (*34*), and in another study, 49% would not be comfortable about asking a family to donate a kidney to them (*45*) but would be prepared to ask for organ transplant from their family to survive and contribute to their family. However, some expressed reluctance "to avoid harming another person" and were unwilling to impose undue obligatory pressure on their family (*48*). They would prefer that their family initiates offers of donation rather than having to ask for a donation.

Donor Autonomy

In two U.S. studies, at least 70% of participants believed that the potential donor should make the final decision, not the physician (*31, 54*). One study found that most respondents believed that the "donor's partner or spouse should be involved in a person's decision to donate, men were even more likely than women to believe this (77% vs. 69%), as were married people (*25*)."

Altruistic, Anonymous Donation

In one study, the majority (80%) of respondents deemed altruistic donation as acceptable (*31*), whereas, in another study, 29% were in favor, 20% were against, and 51% were undecided about donation to an unknown recipient (*13*). There was also a view held by members of the public that the only factor substantiating grounds for living donation was having a personal relationship with the potential recipient (*55*). Anonymous donors were viewed as extremes of either "incredible selfless or incredibly stupid…obviously extremely kind hearted…[or]…on the edge of insanity," and some participants doubted their motives for donating (*50*). Most believed that donors should not be able to direct their donation to a specific group according to, for example, race and religion (*47*).

Compensation and Incentives for Living Donors

The majority of respondents in studies conducted within the United Kingdom, Europe, and United States were in favor of financial reimbursement for donor out-of-pocket expenses and felt it was legitimate (*25, 54–56*). Moreover, they supported paid leave (*25, 54, 56*) (although pro-rata in terms of "time of work" was not discussed), wait-listing priority (*56*), lifelong health insurance (*36*), and donor acknowledgment (*55*). However, they indicated less preference for government tax breaks (*56*) and financial incentives from health insurance companies (*36*).

In studies that were conducted in Europe and Canada, most were opposed to financial incentives and a regulated market for paid donation (19%–26% would support paid donation) (*43, 54*). An argument against the commercialization of living organ donation was the incommensurable value of an organ.

The public largely rejected commercial transplantation as they believed it might lead to potential exploitation and inequity and would diminish voluntary altruism (*55, 57, 58*). Commercial living donation was expressed as being analogous to "slavery" and "cannibalism" (*57*), although one respondent in a study stated that "there is fine line between compassion and exploitation" (*57*). In a study conducted in Europe, participants believed that organ trafficking highlighted the need to enact moral responsibility by improving donation rates and achieve national sufficiency (*55*).

Two studies (*25, 36*) found that younger people were more likely to support payment for donation, which Kranenburg et al. (*36*) speculate could be explained by changing societal values and more liberal attitudes of the younger population. A small proportion of participants would consider donating an organ for financial compensation, particularly if they were experiencing financial difficulty (*14, 36, 43*).

In the context of a regulated market for paid organ donation, most respondents believed that professional health organizations, the government, or international organizations such as the World Health Organization should be responsible for the system (*57*). However, participants doubted the feasibility of implementing regulation and acknowledged that tight regulation would be needed (*57*).

DISCUSSION

The majority of the general public were in favor of living direct donation. Most were supportive and in principle willing to donate to their child, spouse, or sibling and, to a lesser extent, toward an older parent, friend, or anonymous recipient. Paired kidney exchange was perceived as a justifiable reciprocity for mutual benefit to the donor–recipient pairs involved. The public believed living donation offered survival and quality-of-life benefits to the recipient and psychosocial advantages to the donor in terms of gaining a sense of reward. However, this endorsement was tempered by concerns about surgical and health risks to the donor, cultural barriers, uncertainty about organ donation, financial loss, lack of trust and confidence in the healthcare system, and potential recipient emotional indebtedness to the donor. Moreover, some would be unwilling to accept a living-donor graft for themselves if there was a risk to the donor and expressed reservations about asking and potentially obliging a family member to accept the risks inherent in being a donor.

Some of the concerns voiced by the public, to some extent, have been addressed in living-donor follow-up studies. Surgical risks are minimal, but some research suggests that donors may be at a slightly increased risk of hypertension, proteinuria, and cardiovascular events (*59, 60*). However, high-quality, long-term outcome data for living donors is lacking, particularly for donors from minority groups and donors with health risk factors. In terms of financial costs to the donor, one systematic review found that living donors incur various costs, including travel and accommodation costs, lost income, and costs for dependent care and domestic help (*61*). Anxieties expressed by the community about potential recipient motional indebtedness to the donor have also been identified in living donors. Studies indicated that donors were conscious to avoid recipient indebtedness by avoiding mention of donation and instead focusing on "moving on" with life (*62*).

Organ trafficking was deemed by the public as unacceptable and global initiatives such as the Declaration of Istanbul (*63*) and legislation are accepted in most countries to prevent or deter commercial transplantation. Polarized views were expressed about anonymous altruistic nondirected donation. Some considered it acceptable and others felt it was unjustifiable because of the lack of a personal relationship and potential nonaltruistic motivations. In this regard, rigorous psychologic assessment is usually required in nondirected donation programs (*1*).

Little is known about public attitudes toward directed donation to a stranger, such as when a potential donor responds to a public appeal in the media or Internet and offers to donate to an individual whom he or she has little or no prior emotional connection. Public solicitation of organs is a difficult and complex issue (*64*). International legislation about noncommercial public solicitation for living donation varies and is illegal in some countries. A survey of 132 U.S. transplant programs found that 30% would accept donors solicited through Web sites or other media outlets (*65*). Debates among professionals and ethicists argue that it may be acceptable based on freedom of choice or fulfillment or moral identity (*66*). On the contrary, the practice raises concerns about potential commercialization and inequity as wealthy, photogenic, and media-savvy individuals with compelling stories are unfairly advantaged (*1*). In the last decade, the emergence of organ donation matching Web sites, such as matchingdonors.com in the United States (also recently launched in the United Kingdom (*67*)), has raised ethical concerns about inequitable allocation and potential profiteering (*1, 64*).

Financial reimbursement for out-of-pocket expenses, paid leave from employment, wait-listing priority in the event of needing a transplant themselves, health insurance, and donor acknowledgment was generally regarded as legitimate. Financial incentives or paid donation were opposed by most based on preserving ethical and moral standards of equity, avoiding exploitation, maintaining voluntary altruism; and doubt over the feasibility of achieving a regulated system for paid donation. These sentiments are shared with most transplant professionals who recognize that incentives to improve living donation must be accompanied by safeguards for vulnerable populations (*68*). Of note, a greater acceptance of paid donation was found among the younger population, which may be explained by the trend toward more liberal attitudes of modern society (*36*). Variations in opinion by geographic or socioeconomic strata could not be determined as public opinion of reimbursement and incentives were addressed by studies conducted only in the western, middle- to high-income countries.

The Ethics Statement of the Vancouver Forum on living donation states that "donor autonomy does not overrule medical judgment and decision making" (*69*), but U.S. studies suggests that the public believes potential donors should make the final decision. This is particularly complex as the level of acceptable mortality and long-term health risk may be different between medical professionals and potential donors. Also, there are different risk profiles, time factors, and clinical contexts to consider for kidney, liver, and also lung lobe donation. The medical and psychosocial screening process, criteria, and thresholds for living-donor acceptance vary between centers (*65*) and there is some concern about accepting "medically complex donors" (*70*). A key consideration in justifying donor rejection is that acceptance of the donor would threaten the public trust (*71*). For these reasons, public input into donor assessment and follow-up policies are warranted.

There are many ethical challenges and uncertainties in living organ donation (*1*). In many countries, strategies to increase living donation include paired and domino-paired kidney exchange, altruistic nondirected donation programs, desensitization of human leukocyte antigen–incompatible pairs, expansion of donor acceptance criteria, and donor reimbursement schemes. More recently, standards for an internationally acceptable system of incentivized organ donation have been proposed (*72*). The extent to which the public has been involved in many of the current debates over public policy in living-donor transplantation is unclear. We have identified a number of gaps in public knowledge and attitudes to living organ donation and suggested broader rigorous canvassing of public perspectives (Table 2).

Currently, the U.K. public are being surveyed about whether registered organ donors should be given priority for transplantation and what changes they deem acceptable in terms of improving deceased donor transplantation rates (*73*). This survey is expected to inform changes to the organ donor and transplantation strategy in the United Kingdom. Likewise, public opinion should be sought to inform rules and policies governing living-donor transplantation. The U.S. Organ Procurement and Transplantation Network issues policy proposals for public comment (*74*), but public opinion needs to be more actively and systematically sought for effective and meaningful contribution to policy.

The study provides a global overview of public perspectives on living organ donation. We used standard systematic review methods, including comprehensive search and screening of studies using predefined inclusion criteria. We included both quantitative and qualitative data to corroborate findings, enhance insights attained with the complementary methodologies, and generate more comprehensive data to help understand public awareness and attitudes regarding living donation. However, there are limitations in our summary estimates due to the wide heterogeneity of the study population, design, and reporting of results. Although the studies were statistically significantly heterogeneous, the magnitude of the responses to each of the questions appeared very similar, with proportions consistently ±10%.

There are little data about the impact of public awareness interventions on living donation rates. Rodrigue et al. (*75*) conducted a randomized controlled study to evaluate the effectiveness of a home-based education program in increasing living-donor kidney transplantation and found that home-based education led to a significant increase in willingness to discuss living kidney donation with others and is effective for increased living-donor kidney transplantation rates. Better understanding about public awareness of living kidney donation can inform community-based educational initiatives to facilitate discussion about living-donor organ transplantation and address misconceptions and concerns about living-donor transplantation. Further research is suggested to assess the impact of public awareness on willingness to be a living donor and thus rates of living-donor transplantation.

In living organ donation, the general community can articulate important equity and ethical considerations for protecting the health and safety of living donors. Neglecting public engagement and input may consequentially lead to potential controversy and distrust in living-donor transplantation programs and policy. This supports the need to promote public engagement and to strengthen a shared view among professionals and the public about living donation practice and policy.

TABLE 2. Proposed research agenda on public attitudes and preferences in living organ donation

Topics	Subtopics
Support for living donation	• Investigate and compare sociocultural and religious beliefs regarding living organ donation
Donor autonomy	• Disaggregate donor autonomy in terms of medical, psychologic, and social risks • Medical professional responsibility and obligations
Informed consent	• Content and delivery of information for potential donors and strategies to ensure that donors receive and understand the information • Maintaining donor and recipient confidentiality
Donor selection	• Considerations for the selection and acceptance of living donors • Strategies to prevent unwarranted coercion or exploitation
Acceptable risk	• Acceptability of expanded criteria for living-donor eligibility (kidney and liver donation) • Preference for content and delivery of risk information (mortality, surgical complications, and short-term and long-term physical and psychosocial outcomes)
Solicitation of living donors	• Attitudes toward public appeals by recipients (via mass media, Web sites, and social networking sites) • Attitudes about initiatives for matching donors with recipients (e.g., matchingdonors.com) • Solicitation of donors within specific communities (e.g., religious communities)
Paired kidney exchange (including domino-paired exchange)	• Perceived benefits and potential risks • Donor and recipient confidentiality in the context of paired kidney exchange
Altruistic nondirected donation	• Screening criteria and acceptability of nondirected donors • Preserving anonymity
Donor follow-up	• Medical and psychosocial follow-up after transplantation
Reimbursement	• Acceptable forms of reimbursement (out-of-pocket expenses, wait-listing priority, and lifetime health insurance) • Donor acknowledgment • Paid leave (responsibility—employers, government, and hospitals; pro rata rates/means testing)
Financially incentivized donation	• Perspectives on organ trafficking and commercial transplantation (consequences for donors/recipients and recipient penalties) • Opinions on current debates on government regulated market for compensation donation

MATERIALS AND METHODS

Selection Criteria

Qualitative studies and surveys that examined the awareness and attitudes of the general public on living organ donation were eligible. This included individuals from the lay public without specialized or professional knowledge of organ donation or transplantation. Articles were excluded if they reported only data elicited from transplant medical professionals, transplant recipients, and organ donors. Epidemiologic studies, editorials, reviews and nonresearch (e.g., guidelines, policy documents, and ethics debates) articles, and articles not published in peer-reviewed journals were also excluded.

Data Sources and Searches

Medical Subject Headings terms and text words for public and community were combined with terms and text words relating to living organ donation and then combined with Medical Subject Headings terms and text words relating to attitude to health, knowledge, attitudes, beliefs, perception, morals, ethics, surveys, and qualitative research (see **Table S5, SDC**, http://links.lww.com/TP/A814). The searches were conducted in Medline, Embase, and PsycINFO from inception to September 2, 2012. We also searched reference lists of relevant articles and reviews, Google Scholar, and PubMed. We screened titles and abstracts and rejected those that did not meet the inclusion criteria. Full texts of potentially relevant studies were obtained and assessed for eligibility.

Study Appraisal

To appraise the surveys, we used a 14-item framework that included the following domains: participant characteristics, survey administration, survey design, and data analysis (*76*). We used the Consolidated Criteria for Reporting Qualitative Health Research to appraise the qualitative studies, which is a 32-item framework for assessing criteria specific to the research team, study methods, context of the study, analysis, and interpretations (*77*).

Data Extraction and Synthesis

Quantitative results were extracted into an electronic database and then tabulated. Where feasible, proportional data were transformed into quantities according to the Freeman-Turkey variant of the arcsine square root transformed proportion (*78*). The pooled proportion was then calculated as the back-transformation of the weighted mean of the transformed proportions using the random effects model by DerSimonian and Laird (*79*). The summary estimates were reported as proportions and the 95% CI, and heterogeneity was analyzed using the I^2 statistic. Preplanned subgroup analyses, such as by organ groups, were used to explore possible sources of heterogeneity, but because of insufficient data, this was not possible. Assessment of publication bias using a funnel plot was not possible due to insufficient studies. All quantitative analyses were done using StatsDirect (StatsDirect Ltd., London, UK, 2005) and SAS software version 9.2 (SAS, Cary, NC).

Given the wide heterogeneity in the study population, the mode and content of surveys, analysis, and reporting of findings, we also conducted a qualitative descriptive synthesis. We extracted all text under the "results/findings" or "conclusion/discussion" section of each article. These were entered verbatim into HyperRESEARCH version 3.0.3 (ResearchWare, Randolph, MA, 2009), software for coding textual data, and then coded under emergent common themes. A.T. recorded all concepts that focused on public perceptions on living organ donation. The textual data were summarized descriptively under common themes inductively derived and identified across all studies.

REFERENCES

1. Truog RD. The ethics of organ donation by living donors. *N Eng J Med* 2005; 353: 444.
2. Gordon EJ. Informed consent for living donation: a review of key empirical studies, ethical challenges and future research. *Am J Transplant* 2012; 12: 2273.
3. Horvat LD, Shariff SZ, Garg AX. Global trends in the rates of living kidney donation. *Kidney Int* 2009; 75: 1088.
4. Mandal AK, Snyder JJ, Gilbertson DT, et al. Does cadaveric donor renal transplantation ever provide better outcomes than live-donor renal transplantation? *Transplantation* 2003; 75: 494.
5. Ommen ES, Winton JA, Murphy B. Medical risks in living kidney donors: absence of proof is not proof of absence. *Clin J Am Soc Nephrol* 2006; 1: 885.
6. Tong A, Chapman JR, Wong G, et al. The motivations and experiences of living kidney donors: a thematic synthesis. *Am J Kidney Dis* 2012; 60: 15.
7. Segev DL, Muzaale AD, Caffo BS, et al. Perioperative mortality and long-term survival following live kidney donation. *J Am Med Assoc* 2010; 303: 959.
8. Matas AJ, Bartlett ST, Leichtman AB, et al. Morbidity and mortality after living kidney donation, 1999–2001: survey of United States transplant centers. *Am J Transplant* 2003; 3: 830.
9. Ratner L, Sandoval P. When disaster strikes: death of a living organ donor. *Am J Transplant* 2010; 10: 2577.
10. Kowalczyk L. At the Lahey, a stunning, rare tragedy: donor dies in liver transplant attempt. *Boston Globe* 2010.
11. Bonifield J, Cohen E. Kidney-donor deaths linked to surgical clips raise issues of alerts, warnings. CNN 2012; 2012.
12. Spital A. Public attitudes toward kidney donation by friends and altruistic strangers in the United States. *Transplantation* 2001; 71: 1061.
13. Conesa C, Rios Zambudio A, Ramirez P, et al. Socio-personal factors influencing public attitude towards living donation in south-eastern Spain. *Nephrol Dial Transplant* 2004; 19: 2874.
14. Rios A, Martinez-Alarcon L, Sanchez J, et al. The quest for favourable subgroups to encourage living kidney donation in Spain. An attitudinal study among British and Irish citizens resident in southeastern Spain. *Nephrol Dial Transplant* 2008; 23: 1720.
15. Mooney GH, Blackwell S. Whose health service is it anyway? Community values in healthcare. *Med J Aust* 2004; 180: 76.
16. Farrell C. *Patient and Public Involvement in Health. The Evidence for Policy Implementation.* London, UK: Department of Health; 2004.
17. Aswad S, Souqiyyeh MZ, Huraib S, et al. Public attitudes toward organ donation in Saudi Arabia. *Transpl Proc* 1992; 24: 2056.
18. Bilgel H, Sadikoglu G, Bilgel N. Knowledge and attitudes about organ donation among medical students. *Transplantation* 2006; 18: 91.
19. Browne C, Desmond DM. Intention to consent to living organ donation: an exploratory study. *Psychol Health Med* 2008; 13: 605.
20. Danguilan RA, De Belen-Uriarte R, Jorge SL, et al. National survey of Filipinos on acceptance of incentivized organ donation. *Transpl Proc* 2012; 44: 839.
21. 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.
22. Pham H, Spigner C. Knowledge and opinions about organ donation and transplantation among Vietnamese Americans in Seattle Washington: a pilot study. *Clin Transplant* 2004; 18: 707.
23. Sobnach S, Borkum M, Hoffman R, et al. Medical students' knowledge about organ transplantation: a South African perspective. *Transpl Proc* 2010; 42: 3368.
24. Landolt MA, Henderson AJ, Barrable WM, et al. Living anonymous kidney donation: what does the public think? *Transplantation* 2001; 71: 1690.
25. Neuberger J, Farber L, Corrado M, et al. Living liver donation: a survey of the attitudes of the public in Great Britain. *Transplantation* 2003; 76: 1260.
26. Rios A, Febrero B, Lopez-Navas A, et al. Evaluation of attitude toward living organ donation among adolescents in southeast Spain. *Transpl Proc* 2012; 44: 1489.
27. Rios A, Conesa C, Ramirez P, et al. Attitudes toward living liver donation among hospital personnel in services not related to transplantation. *Transpl Proc* 2005; 37: 3636.
28. Rios A, Febrero B, Martinez-Alarcon L, et al. Evaluation of attitudes toward living organ donation: a multicenter study of compulsory secondary school education teachers. *Transpl Proc* 2010; 42: 3106.
29. Rios A, Martinez-Alarcon L, Sanchez J, et al. Factors that influence the attitude of East European residents in Spain towards living kidney donation. *Transpl Int* 2009; 22: 707.
30. Siegel JT, Alvaro EM, Lac A, et al. Intentions of becoming a living organ donor among Hispanics: a theory-based approach exploring differences between living and nonliving organ donation. *J Health Commun* 2008; 13: 80.

31. Spital A, Spital M. Living kidney donation. Attitudes outside the transplant center. *Arch Intern Med* 1988; 148: 1077.
32. Al-Faqih SR. The influence of Islamic views on public attitudes towards kidney transplant donation in a Saudi Arabian community. *Public Health* 1991; 105: 161.
33. Boulware LE, Ratner LE, Sosa JA, et al. Determinants of willingness to donate living related and cadaveric organs: identifying opportunities for intervention. *Transplantation* 2002; 73: 1683.
34. Colak M, Ersoy K, Haberal M, et al. Household study to determine attitudes and beliefs related to organ transplantation and donation: a pilot study in Yapracik Village, Ankara, Turkey. *Transpl Proc* 2008; 40: 29.
35. Dahlke MH, Popp FC, Eggert N, et al. Differences in attitude toward living and postmortal liver donation in the United States, Germany, and Japan. *Psychosomatics* 2005; 46: 58.
36. Kranenburg L, Schram A, Zuidema W, et al. Public survey of financial incentives for kidney donation. *Nephrol Dial Transplant* 2008; 23: 1039.
37. Landolt MA, Henderson AJZ, Gourlay W, et al. They talk the talk: surveying attitudes and judging behavior about living anonymous kidney donation. *Transplantation* 2003; 76: 1437.
38. Martinez-Alarcon L, Rios A, Lopez MJ, et al. The attitude of future journalists toward living donation. *Transpl Proc* 2009; 41: 2055.
39. Meng OY, Lim C, Leng CW, et al. Factors influencing living kidney donation in Singapore. *Prog Transplant* 2012; 22: 95.
40. Morgan M, Hooper R, Mayblin M, et al. Attitudes to kidney donation and registering as a donor among ethnic groups in the UK. *J Public Health* 2006; 28: 226.
41. Munoz Sastre MT, de Sousa S, Bodi E, et al. Under what conditions would people be willing to make a living organ donation? *Psychol Health Med* 2012; 17: 323.
42. Piccoli GB, Soragna G, Putaggio S, et al. To give or to receive? Opinions of teenagers on kidney donation. *Transpl Proc* 2004; 36: 448.
43. Rid A, Bachmann LM, Wettstein V, et al. Would you sell a kidney in a regulated kidney market? Results of an exploratory study. *J Med Ethics* 2009; 35: 558.
44. Segev DL, Powe NR, Troll MU, et al. Willingness of the United States general public to participate in kidney paired donation. *Clin Transplant* 2012: doi: 10.1111/j.1399.
45. Siegel JT, Alvaro EM, Hohman ZP, et al. "Can you spare an organ?": exploring Hispanic Americans' willingness to discuss living organ donation with loved ones. *Health Commun* 2011; 26: 754.
46. Teo TT, Hossain MM, Zinna S, et al. Public opinion on renal transplantation in Brunei Darussalam. *Transpl Proc* 2011; 43: 3599.
47. Spital A. Should people who donate a kidney to a stranger be permitted to choose their recipients? Views of the United States public. *Transplantation* 2003; 76: 1252.
48. Alvaro EM, Siegel JT, Turcotte D, et al. Living kidney donation among Hispanics: a qualitative examination of barriers and opportunities. *Prog Transplant* 2008; 18: 243.
49. Exley C, Sim J, Reid N, et al. Attitudes and beliefs within the Sikh community regarding organ donation: a pilot study. *Soc Sci Med* 1996; 43: 23.
50. Hyde MK, White KM. Knowing a donor and identifying as one: determinants of people's willingness for related and anonymous living donation in Australia. *Psychol Health Med* 2009; 14: 524.
51. Hyde MK, White KM. Student and community perceptions about organ donors, non-donors and transplant recipients. *J Community Appl Soc Psychol* 2009; 19: 125.
52. Boulware LE, Ratner ER, Sosa JA, et al. The general public's concerns about clinical risk in live kidney donation. *Am J Transplant* 2002; 2: 186.
53. Molzahn AE, Starzomski R, McDonald M, et al. Chinese Canadian beliefs toward organ donation. *Qual Health Res* 2005; 15: 82.
54. Cotler SJ, McNutt R, Patil R, et al. Adult living donor liver transplantation: preferences about donation outside the medical community. *Liver Transpl* 2001; 7: 335.
55. Schweda M, Schicktanz S. Public ideas and values concerning the commercialization of organ donation in four European countries. *Soc Sci Med* 2009; 68: 1129.
56. Boulware LE, Troll MU, Wang NY, et al. Public attitudes toward incentives for organ donation: a national study of different racial/ethnic and income groups. *Am J Transplant* 2006; 6: 2774.
57. Guttmann A, Guttmann RD. Attitudes of healthcare professionals and the public towards the sale of kidneys for transplantation. *J Med Ethics* 1993; 19: 148.
58. Piccoli GB, Putaggio S, Soragna G, et al. Kidney vending: opinions of the medical school students on this controversial issue. *Transpl Proc* 2004; 36: 446.
59. Garg AX, Muirhead N, Knoll G, et al. Proteinuria and reduced kidney function in living kidney donors: a systematic review, meta-analysis, and meta-regression. *Kidney Int* 2006; 70: 1801.
60. Boudville N, Prasad GV, Knoll G, et al. Meta-analysis: risk for hypertension in living kidney donors. *Ann Intern Med* 2006; 145: 185.
61. Clarke KS, Klarenback S, Vlaicu S, et al. The direct and indirect costs incurred by living kidney donros—a systematic review. *Nephrol Dial Transplant* 2006; 21: 1952.
62. Gill P, Lowes L. Gift exchange and organ donation: donor and recipient experiences of live related kidney transplantation. *Int J Nurs Stud* 2008; 45: 1607.
63. The Declaration of Istanbul on Organ Trafficking and Transplant Tourism. *Nephrol Dial Transplant* 2008; 23: 3375.
64. Steinbrook R. Public solicitation of organ donors. *N Eng J Med* 2005; 353: 441.
65. Rodrigue JR, Pavlakis M, Danovitch GM, et al. Evaluating living kidney donors: relationship types, psychosocial criteria, and consent processes at US transplant programs. *Am J Transplant* 2007; 7: 2326.
66. Hillhorst MT. Directed altruistic living organ donation: partial but not unfair. *Ethic Theory Moral Pract* 2005; 8: 197.
67. Limb M. New guidance on donating organs is issued amid fears of attempts to profit from giving. *Br Med J* 2012; 345: doi: 10.1136/bmj.e6141
68. Israni AK, Halpern SD, Zink S, et al. Incentive models to increase living kidney donation: encouraging without coercing. *Am J Transplant* 2005; 5: 15.
69. Pruett T, Tibell A, Alabdulkareem A, et al. The ethics statement of the Vancouver Forum on live lung, liver, pancreas, and intestine donor. *Transplantation* 2006; 81: 1386.
70. Reese PP, Feldman HI, McBride MA, et al. Substantial variation in the acceptance of medically complex live kidney donors across US renal transplant centers. *Am J Transplant* 2008; 8: 2062.
71. Steiner RW. Risk appreciation for living kidney donors: another new subspecialty? *Am J Transplant* 2004; 4: 694.
72. Working Group on Incentives for Living Donation. Incentives for organ donation: proposed standards for an internationally acceptable system. *Am J Transplant* 2012; 12: 306.
73. Torgjesen I. Organ donors could be given priority for transplants under new rules. *Br Med J* 2012; 345: doi: 10.1136/bmj.e5219.
74. OPTN. Policy Proposals Issued for Public Comment Release Date 09/21/2012. Available at http://optn.transplant.hrsa.gov/news/newsDetail.asp?id=1580. Rockville, MD: Health Resources and Service Administration, 2012.
75. Rodrigue JR, Cornell DL, Lin JK, et al. Increasing live donor kidney transplantation: a randomized controlled trial of a home-based educational intervention. *Am J Transplant* 2007; 7: 694.
76. Tong A, Howard K, Jan S, et al. Community preferences for the allocation of solid organs for transplantation: a systematic review. *Transplant* 2010; 89: 796.
77. Tong A, Sainsbury P, Craig JC. Consolidated Criteria for Reporting Qualitative Research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care* 2007; 19: 349.
78. Stuart A, Ord K, Arnold S, et al. *Kendall's Advanced Theory of Statistics.* 6th ed. London: Oxford University Press; 2005.
79. DerSimonian R, Laird N. Meta-analysis in clinical trials. *Control Clin Trials* 1986; 7: 177.
80. El-Shoubaki H, Bener A. Public knowledge and attitudes toward organ donation and transplantation: a cross-cultural study. *Transpl Proc* 2005; 37: 1993.
81. AlKhawari FS, Stimson GV, Warrens AN. Attitudes toward transplant in UK Muslim Indo-Asians in West London. *Am J Transplant* 2005; 5: 1326.
82. Schweda M, Wohlke S, Schicktanz S. Understanding public skepticism toward organ donation and its commercialization: the important role of reciprocity. *Transpl Proc* 2009; 41: 2509.