

# Donor Information for Living Donor Liver Transplantation: Where Can Comprehensive Information Be Found?

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Recently published data show that a large number of candidates for living donor liver transplantation (LDLT) actively look for additional information on the Internet because today it represents the main source of information for many of them. However, little is known about the quality of the information on LDLT available on the Internet. Our aim was, therefore, to comprehensively evaluate the online information available for LDLT candidates with the expanded Ensuring Quality Information for Patients (EQIP) tool (0–36 items). One hundred Web sites on LDLT were initially found with the Google, Bing, and Yahoo search engines, and we identified 32 Web sites that provided specific information for such candidates in English. Only 9 Web sites addressed >20 items and the scores tended to be higher for educational ( $P = 0.13$ ) and scientific sites ( $P = 0.07$ ) compared to hospital sites. The median number of items from the EQIP tool was only 16 (interquartile range = 13–20), and quantitative postoperative morbidity and mortality risk estimates were available on only 19% and 44% of the Web sites, respectively, despite the idea of major complications being mentioned on most Web sites. This analysis demonstrated several significant shortcomings in the quality of the information provided to potential donors for LDLT according to the EQIP instrument. We conclude that there is an urgent need to produce a Web site compliant with international standards for the quality of donor information. *Liver Transpl* 18:892–900, 2012. © 2012 AASLD.

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Transparent, objective, and well-structured information concerning the risks of living donor liver transplantation (LDLT) for potential donors is paramount. Patient decision aids such as printed documents and online sources of information are known to dramatically increase the involvement of patients in the decision-making process and thereby also increase the value of informed consent.<sup>1</sup> Although it is the responsibility of each center to provide precise and professional medical information,<sup>2</sup> a large number of candidates for living donation, including LDLT donors, use the Internet as a complementary source for education.<sup>3,4</sup> However, despite efforts toward standardiza-

tion,<sup>5</sup> health information on the Internet varies greatly in its quality, accuracy, and readability.<sup>6</sup>

Many sources of information on the Internet refer more generally to living donation. However, most of the Web sites include sections specially dedicated to liver procurement and kidney procurement, which are the living donation procedures most commonly performed worldwide. In the setting of living kidney procurement, most online information has been found to be incomplete with a need for significant improvement.<sup>7</sup>

Many referral centers have developed their own Web sites to comply with the need to provide adequate information to living donors. Using the Web-based Delphi consensus process, the International Patient Decision Aids Standards (IPDAS) collaboration has established precise recommendations and guidelines

Abbreviations: EQIP, Ensuring Quality Information for Patients; IPDAS, International Patient Decision Aids Standards; IQR, interquartile range; LDLT, living donor liver transplantation; NA, not applicable.

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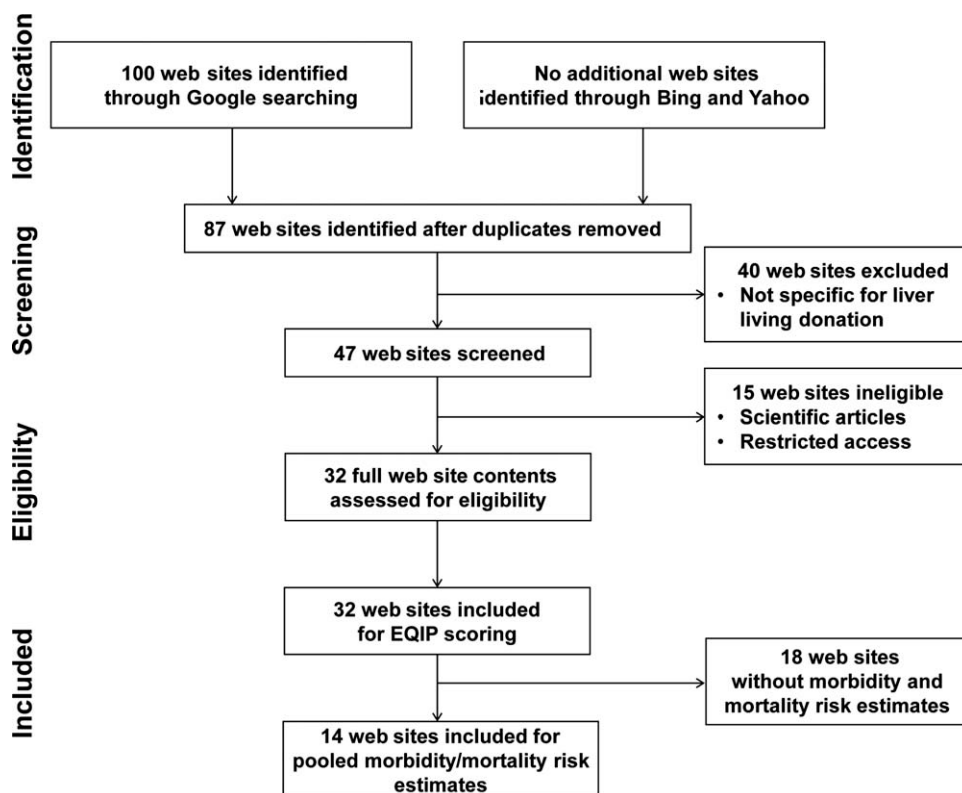


Figure 1. Flow of information through the phases of the systematic search. Adapted with permission from *International Journal of Surgery*.<sup>14</sup> Copyright 2010, Elsevier.

for developers of new decision aids in health care.<sup>1</sup> Instead of a quality rating scale, the IPDAS collaboration provides a checklist for determining whether patient decision aids include content and process items judged to be important.<sup>8</sup> To assess the quality of patient decision aids, new validated tools such as the Ensuring Quality Information for Patients (EQIP) instrument<sup>9</sup> are available. The EQIP instrument is a convenient checklist that is applicable to all information types, and it recently has been expanded<sup>10</sup> to meet many criteria of the British Medical Association patient information appraisal form<sup>11</sup> and the IPDAS collaboration.<sup>1</sup> However, the EQIP instrument includes fewer items than the IPDAS checklist and considers only quality, readability, and design aspects of written information. The EQIP instrument has proved to be useful in other studies evaluating patient information aids,<sup>12,13</sup> but to the best of our knowledge, it has never been used to evaluate donor information in the setting of LDLT. In this study, we aimed to analyze the quality of donor information for LDLT on the Internet with the expanded EQIP instrument.

## PATIENTS AND METHODS

### Eligibility Criteria, Information Sources, and Study Selection

Data were collected with the Google, Bing, and Yahoo search engines. The key words *liver*, *living*, and *donor* were selected and used in various combinations to find Web sites dedicated to donor medical informa-

tion. The first 100 Web sites from each search engine were considered because we assumed that most people limit their searches to a number well below 100. All Web sites directing readers to articles in scientific journals were excluded because donors are not expected to have access to this restricted source of information. The Web sites were then divided into 3 groups according to their origin: (1) hospital services, (2) scientific societies, and (3) educational groups. Figure 1 illustrates the flow of information through the various phases of our systematic review.

In addition, because a large number of LDLT procedures are performed in Asian countries,<sup>15</sup> 2 independent native Japanese and Chinese speakers simply screened the number of available Web sites on the Internet providing donor information for LDLT; they used the key words *liver*, *living*, and *donor* in their native languages. Those Web sites, however, were not included in our systematic analysis because of our linguistic limitations.

### Donor Medical Information Evaluation Tool

We used the expanded EQIP instrument to assess each Web site.<sup>10</sup> Briefly, this instrument is composed of 36 items (or criteria) that assess the content, identification, and structure data of patient information documents (Table 1). The EQIP tool originally included a rating scale of 4 options: yes, partly yes, no, and not applicable (NA). We decided to use the binary scale of yes versus no or NA (ie, no points) for items NA to living liver donors. We did not use the

**TABLE 1. Criteria for the Evaluation of Donor Information Document Quality and Overall Response Rates to Each Item (or Criteria)**

	Criteria	Included or NA	Number of Web Sites	%
<b>Content data</b>				
Item 1	Initial definition of which subjects will be covered	Yes	29	91
		No	3	9
Item 2	Coverage of the previously defined subjects (NA if the answer is "no" for item 1)	Yes	26	81
		No	6	19
Item 3	Description of the medical problem (of the recipient)	Yes	8	25
		No	24	75
Item 4	Definition of the purpose of the surgical intervention	Yes	31	97
		No	1	3
Item 5	Description of treatment alternatives (in this context, description of deceased liver transplantation option)	Yes	19	59
		No	13	41
Item 6	Description of the sequence of the surgical procedure	Yes	21	66
		No	11	34
Item 7	Description of the qualitative benefits to the recipient (eg, shortened waiting time)	Yes	19	59
		No	13	41
Item 8	Description of the quantitative benefits to the recipient (eg, up to 20% survival advantage)	Yes	7	22
		No	25	78
Item 9	Description of the qualitative risks and side effects	Yes	19	59
		No	13	41
Item 10	Description of the quantitative risks and side effects (eg, "two-thirds of patients experience a biliary leak")	Yes	17	53
		No	15	47
Item 11	Addressing quality-of-life issues	Yes	10	31
		No	22	69
Item 12	Description of how complications are handled	Yes	1	3
		No	31	97
Item 13	Description of the precautions that the patient may take	Yes	4	12
		No	28	88
Item 14	Mention of alert signs that the patient may detect	Yes	1	3
		No	31	97
Item 15	Addressing medical intervention costs and insurance issues	Yes	11	34
		No	21	66
Item 16	Specific contact details for hospital services (NA if not hospitals)	Yes	20	62
		No	2	6
		NA	10	31
Item 17	Specific details of other sources of reliable information/support	Yes	20	62
		No	12	38
Item 18	Coverage of all relevant issues for the topic (summary item for all content criteria)	Yes	0	0
		No	32	100
<b>Identification data</b>				
Item 19	Date of issue or revision	Yes	12	37
		No	20	63
Item 20	Logo of the issuing body	Yes	32	100
		No	0	0
Item 21	Names of the persons or entities that produced the document	Yes	19	59
		No	13	41
Item 22	Names of the persons or entities that financed the document	Yes	0	0
		No	32	100
Item 23	Short bibliography of the evidence-based data used in the document	Yes	6	19
		No	26	81
Item 24	Statement about whether and how patients were involved/consulted in the document's production	Yes	1	3
		No	31	97
<b>Structure data</b>				
Item 25	Use of everyday language and explanation of complex words or jargon	Yes	28	88
		No	4	12
Item 26	Use of generic names for all medications or products (NA if no medications described)	Yes	2	6
		No	1	3
		NA	29	91
Item 27	Use of short sentences (<15 words on average)	Yes	19	59
		No	13	41

TABLE 1. (Continued)

	Criteria	Included or NA	Number of Web Sites	%
Item 28	Personal address to the reader	Yes	19	59
		No	13	41
Item 29	Respectful tone	Yes	31	97
		No	1	3
Item 30	Clear information (no ambiguities or contradictions)	Yes	21	66
		No	11	34
Item 31	Balanced information on risks and benefits	Yes	14	44
		No	18	56
Item 32	Presentation of information in a logical order	Yes	25	78
		No	7	22
Item 33	Satisfactory design and layout (excluding figures or graphs; see next item)	Yes	10	31
		No	22	69
Item 34	Clear and relevant figures or graphs (NA if absent)	Yes	7	22
		No	4	12
		NA	21	66
Item 35	Inclusion of a named space for the reader's notes or questions	Yes	1	3
		No	31	97
Item 36	Inclusion of a printed consent form contrary to recommendations (NA if not from hospitals)	Yes	2	6
		No	20	62
		NA	10	31

NOTE: The criteria are based on the expanded EQIP instrument.<sup>10</sup>

original scale because of the subjective nature of the answer *partly yes*, which is associated with low reliability for the assessment of Web sites as reported by other studies.<sup>9,16</sup> Because of the sensitive topic of living donation, we felt that only a comprehensive description of the LDLT procedure for the donor should be considered acceptable for patient decision aids.

For all Web sites providing links to other sources of information, the EQIP criteria were also applied to the information provided by the links. The results were then included in the overall assessment of the original Web site. According to the EQIP instrument, hospital services should not include in their information documents (or on their Web sites) an informed consent form, so hospital services providing such documents on their Web sites received a negative point (item 36; Table 1). Furthermore, item 18 (Table 1) gives extra credit if all the content data items are addressed properly on a Web site.

Notably, it is recommended by the EQIP instrument and the IPDAS collaboration that an information document should include tools such as worksheets or a named space for the reader's notes to discuss options with others. This criterion is assessed by item 35 (Table 1) and is designed to reinforce the partnership between the clinician and the patient and to remind the patient to take note of questions to ask or instructions to follow.<sup>9</sup>

### Description of the Benefits of LDLT for the Recipient

This issue is addressed by items 7 and 8 of the EQIP instrument (Table 1). Item 7 assesses the description

of the recipient's qualitative benefits from LDLT versus cadaveric donor liver transplantation [ie, whether a Web site simply lists the benefits of LDLT (eg, a shortened waiting time, a healthier donor organ, scheduled surgery, and a better outcome)]. Item 8 assesses the description of the recipient's quantitative benefits from LDLT versus cadaveric donor liver transplantation [ie, whether literature-based estimates of the survival advantage (eg, up to a 20% 5-year survival advantage<sup>15</sup>) and/or the reduction in the recipient's risk of death (eg, up to a 13% postoperative mortality risk<sup>15</sup>) are provided on a Web site].

### Morbidity and Mortality Risks for the Donor

Information on morbidity and mortality risks is assessed by items 9 and 10 of the EQIP instrument (Table 1). Item 9 assesses the description of the qualitative risks of LDLT [ie, whether a Web site simply lists the risks of postoperative complications (eg, hemorrhaging, biliary leaks, and/or pulmonary complications)]. Item 10 assesses the description of the quantitative risks of LDLT [ie, whether the estimated risks of morbidity and mortality, based on the literature, are clearly provided on a Web site (eg, a 0.2%-1% risk of postoperative death<sup>15,17</sup>)].

### Psychosocial Risks

This dimension is assessed by item 11, which addresses quality-of-life issues and includes a description of mental well-being (eg, the risk of depression), ability, and the time to full employment after the surgery.

TABLE 2. Analyzed Web Sites (n = 32) according to the Types, Scores, and Morbidity and Mortality Risk Estimates

Web Site	Type	Score	Morbidity (%)	Mortality (%)
British Columbia Transplant <sup>19</sup>	Scientific	28		0.5
University Health Network <sup>20</sup>	Hospital	25	30	0.1-0.3
National Health Service Scotland <sup>21</sup>	Scientific	25	20	0.5-1
London Health Science Centre <sup>22</sup>	Hospital	24		
Benioff Children's Hospital (University of California San Francisco) <sup>23</sup>	Hospital	23		
Trillium Gift of Life Network <sup>24</sup>	Educational	22		0.2-0.5
International Association of Living Organ Donors <sup>25</sup>	Educational	21	20	0.5-1
Wikipedia <sup>26</sup>	Educational	20		0.5-1
American Society of Transplantation <sup>27</sup>	Scientific	20		
Transplant Living <sup>28</sup>	Educational	19		
University of Pittsburgh Medical Center <sup>29</sup>	Hospital	19		
Virginia Commonwealth University Medical Center <sup>30</sup>	Hospital	19		
National Institute for Health and Clinical Excellence <sup>31</sup>	Scientific	18	16	0.2-0.5
Children's Memorial Hospital <sup>32</sup>	Hospital	18		
Liver Transplant Program and Center for Liver Disease (University of Southern California Department of Surgery) <sup>33</sup>	Hospital	17		
eMedTV <sup>34</sup>	Educational	16		1
Mayo Clinic <sup>35</sup>	Hospital	16		0.3-0.5
University of California Los Angeles Health System <sup>36</sup>	Hospital	15		
University of California San Francisco Medical Center <sup>37</sup>	Hospital	15		
Columbia University Department of Surgery <sup>38</sup>	Hospital	15		
Mount Sinai Hospital <sup>39</sup>	Hospital	15		
Duke University Health System <sup>40</sup>	Hospital	14		<1
eMedicineHealth <sup>41</sup>	Educational	14		1
Cedars-Sinai <sup>42</sup>	Hospital	13		
Penn Transplant Institute <sup>43</sup>	Hospital	13	15-30	0.2
Stanford Hospital & Clinics <sup>44</sup>	Hospital	12	15	<1
eHow Health <sup>45</sup>	Educational	12		
NewYork-Presbyterian Hospital <sup>46</sup>	Hospital	12		
University of Minnesota Medical Center <sup>47</sup>	Hospital	11		
HCV Advocate <sup>48</sup>	Scientific	11		0.2
John Hopkins Medicine <sup>49</sup>	Hospital	9		
Jefferson University Hospitals <sup>50</sup>	Hospital	9		

## Statistical Analysis

Statistical analysis was performed with SPSS 19 for Mac (SPSS, Inc., Chicago, IL). Categorical data were compared with Fisher's exact tests or  $\chi^2$  tests, and continuous variables were compared with Student *t* tests or 1-way analyses of variance as appropriate. All *P* values were 2-sided and were considered to have achieved statistical significance at  $P \leq 0.05$ . Web sites were scored from 0 to 36 according to the number of addressed items from the expanded EQIP instrument. Thus, each criterion was given equal weight of importance. We chose to dichotomize the EQIP score (a continuous variable) by using the arbitrary 75th quartile as a cutoff point for discriminating high-score Web sites from low-score Web sites.<sup>18</sup> All Web sites were assessed by 2 independent investigators (E.M. and D.A.R.). The measurement of the level of agreement between the 2 examiners was performed with Cohen's  $\kappa$  test for the different items used to assess the Web sites. This measure calculates the degree of agreement in classification over what would be expected by chance, and it is scored as a number between 0 and 1: >0.79, excellent agreement; 0.59, good agreement;

0.39, moderate agreement; 0.2, poor agreement; and <0.2, no agreement. Similarly, the intraclass correlation coefficient test was used to correlate the scores derived from evaluations by the 2 investigators (2-way mixed effects: rater effects were random, measure effects were fixed, and there was excellent correlation when *r* was >0.9).

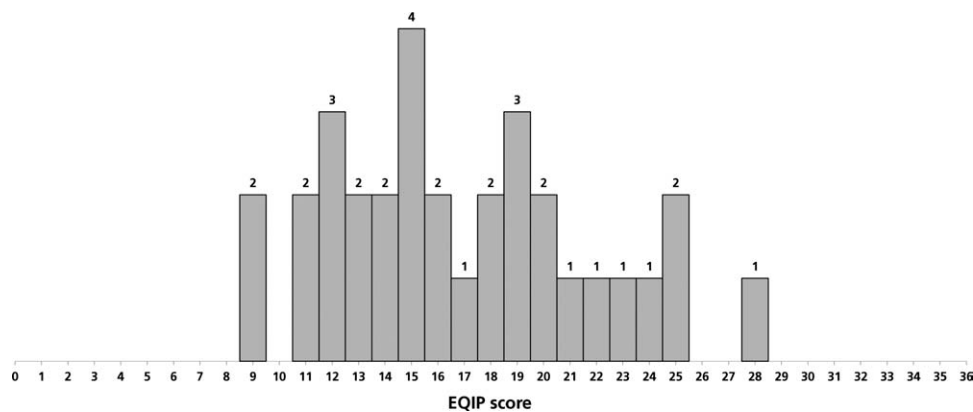
## RESULTS

### Web Sites With Donor Medical Information

With the key words *liver*, *living*, and *donor*, 5,320,000 Web sites were identified by Google, 7,840,000 were identified by Bing, and 17,100,000 were identified by Yahoo (June 2011). Thirty-two of the 100 initial Web sites from Google included donor medical information for LDLT (Table 2). No additional Web sites were identified with the Bing and Yahoo engines. Twenty of those 32 Web sites (62%) were developed by hospital services, 5 (16%) were developed by scientific groups, and 7 (22%) were developed by educational groups. In addition, only 10 Japanese Web sites (7 from hospital services and 3 from educational groups) and 8



Figure 2. Number of Web sites according to the scoring system. The score was calculated according to the total number of EQIP items<sup>10</sup> included on the Web sites. Each item was given 1 point, and the median score was 16 (IQR = 13-20).



Chinese Web sites (5 from hospital services and 3 from educational groups) included donor medical information for LDLT.

### Interobserver Agreement

The intraclass correlation coefficient for the 36 items of the EQIP instrument rated by the 2 investigators (E.M. and D.A.R.) was 0.992 (95% CI = 0.983-0.996,  $P < 0.001$ ). The level of agreement was excellent for all items ( $\kappa = 0.8-1.0$ ) except for items 24 and 32, for which the  $\kappa$  values were good (0.65 and 0.76, respectively). The authors then met and agreed by consensus about the correct ratings for the items about which they had initially disagreed.

### Overall Quality of Donor Medical Information According to the EQIP Instrument

The median number of items from the EQIP tool addressed on the 32 Web sites was only 16 [interquartile range (IQR) = 13-20; Fig. 2]. The top items addressed on >80% of the Web sites included items 1 (91%), 2 (81%), 4 (97%), 20 (100%), 25 (88%), and 29 (97%; Table 1). Item 1 concerns the initial definition of which subjects will be covered (ie, what is LDLT?); item 2 concerns the coverage of the subject of LDLT; item 4 concerns the definition of the purpose of the surgical intervention; item 20 concerns the logo of the issuing body (ie, the organization that produced and updated the Web site); item 25 concerns the use of everyday language and the explanation of complex words or jargon; and item 29 concerns the use of a respectful tone. The 2 items never addressed on the different Web sites were items 18 and 22 (Table 1). Item 18 concerns the document's coverage of all relevant issues for the topic (summary item for all content criteria), and item 22 concerns the names of the entities that financed the document. As listed in Table 2, 2 Web sites for hospital services (Jefferson University Hospitals<sup>50</sup> and John Hopkins Medicine<sup>49</sup>) fulfilled fewer than 10 items, and none of the 32 documents addressed all 36 items from the EQIP instrument. The site that addressed the highest number of items (score = 28) was developed by a scientific society (British Columbia Transplant<sup>19</sup>). With a cutoff score of 20

(corresponding to the 75th percentile), 9 Web sites addressed 20 or more items from the EQIP instrument (ie, higher score sites). Although the difference was not significant, the scores tended to be higher for educational ( $P = 0.13$ ) and scientific sites ( $P = 0.07$ ) in comparison with hospital sites.

A comparative analysis of high-score and low-score Web sites identified 10 items that were significantly more often addressed on the high-score Web sites: item 7 (89% versus 48%,  $P = 0.05$ ), item 9 (89% versus 48%,  $P = 0.05$ ), item 11 (78% versus 13%,  $P = 0.001$ ), item 13 (44% versus 0%,  $P = 0.004$ ), item 19 (78% versus 22%,  $P = 0.006$ ), item 21 (89% versus 48%,  $P = 0.05$ ), item 28 (89% versus 48%,  $P = 0.05$ ), item 30 (100% versus 52%,  $P = 0.01$ ), item 31 (64% versus 36%,  $P < 0.01$ ), and item 33 (67% versus 17%,  $P = 0.01$ ; Table 1). Notably, only 4 content items were addressed on the high-score Web sites; these items included descriptions of qualitative benefits of LDLT for the recipient (item 7), qualitative risks and side effects for the donor (item 9), quality-of-life issues (item 11), and precautions that the donor may take (item 13).

### Web Site Content: Description of Morbidity and Mortality Risks

Nineteen Web sites (59%) listed the qualitative risks of LDLT for the donor. Mainly, the risks of biliary, pulmonary, and wound complications were properly listed. Estimates of the morbidity and mortality rates for donors (ie, the quantitative risks) were provided by only 6 (19%) and 14 (44%) of the Web sites, respectively (Table 2). The pooled median morbidity and mortality risk rates were 20% (minimum = 15%, maximum = 30%, IQR = 17%-28%) and 0.75% (minimum = 0.2%, maximum = 1%, IQR = 0.23%-1.00%), respectively. Only 1 educational Web site (eMedTV<sup>34</sup>) specifically provided a 6% estimated risk of biliary complications, and 1 Web site originating from a hospital services (University Health Network<sup>20</sup>) provided a 5% estimated risk of reoperation according to the literature. Finally, a description of the ways in which complications are handled (item 12) and a description of the precautions that the donor may take before or

after surgery (item 13) were rarely explained [3% ( $n = 1$ ) and 12% ( $n = 4$ ) of the Web sites, respectively].

## DISCUSSION

To the best of our knowledge, this is the first study evaluating donor information on the Internet for LDLT with a validated tool (ie, the EQIP instrument). The results of this study show a disturbing lack of information for LDLT donors on the Internet, and surprisingly, none of the analyzed Web site met the 36 criteria of the EQIP instrument, so they only partially met the international standards for quality patient information.

In the setting of living kidney transplantation, it has been shown that potential donors who use the Internet as a source of information are often more comfortable with the procedure than individuals who do not conduct such research.<sup>51</sup> However, most online information has been found to be incomplete with a need for improvement.<sup>7</sup> Although most transplant centers provide potential donors with an information document that describes the LDLT procedure, candidates for LDLT are seeking further complementary information.<sup>4</sup> Searching the Internet, reading articles, and speaking to other donors are activities of great value for potential donors.<sup>4</sup> The 24-hour availability of the Internet offers them a timely, independent source of information that can be read at home without stress. One might suggest that many donors have already decided to donate before they look for any information on the Internet. On the other hand, it has been shown that after using patient information aids, many candidates have already decided to donate before they contact the transplant center.<sup>3,51</sup> This implies that donor information available on the Internet should be comprehensive and accurate.

According to our analysis, the available Web sites addressed a median of only 16 of the 36 items derived from a standardized questionnaire (the EQIP instrument). According to this analysis, the description of the LDLT procedure, the alternatives to living donation (ie, deceased donors), and the morbidity and mortality risks for the donors were insufficiently addressed by the 32 available Web sites. In addition, only 1 Web site properly addressed whether and how patients were involved and/or consulted in the production of the Web site, and this is an important requirement for the delivery of quality information.<sup>10</sup>

More than half of the Web sites providing donor information for LDLT were developed by hospital services. In contrast, most high-score Web sites (ie, Web sites addressing 20 or more items from the EQIP instrument) came from educational or scientific groups. Because the educational group Web sites originated mostly from living donor related transplant associations, we can speculate that these organizations might be more sensitive to the expectations of the donors. The fact that Web sites developed by scientific societies scored higher is also somewhat expected because of their mission and the availability

of specific working groups. Thus, scientific group Web sites can provide more accurate and objective information than most individual centers, and it might be suggested that hospital services just refer donors to the Web sites of scientific societies instead of developing their own sites. We speculate that the rationale for center-oriented Web sites is mostly marketing-driven.

One other striking result of our study is the infrequent reporting of estimates of donor morbidity and mortality risks on Web sites. This information is of primary concern for LDLT candidates who are considering the procedure. Although in some countries centers might find it important to discuss center-specific rates, the EQIP instrument and the IPDAS collaboration recommend that all scientific data reported on Web sites be evidence-based and referenced to prevent confusion and doubts about the reliability of the procedure. Several Web sites listed and explained potential complications for the donor (eg, biliary and pulmonary complications and hemorrhagic risk); however, the quantification of the risks of each complication (eg, up to a 37% risk of biliary leakage<sup>15,52</sup>) was infrequently addressed. Moreover, the estimated mortality risk (0.2%-1%<sup>15,53</sup>) was addressed by only 44% of the Web sites. Only 6 Web sites (19%) gave precise quantitative morbidity rates (range = 15%-30%) consistent with the available literature.<sup>15,54</sup> Finally, only 6 Web sites (19%) included both morbidity and mortality rates.

According to our reliability analysis, the EQIP instrument is a reproducible tool, and this is consistent with the findings of other studies.<sup>10,13</sup> The  $\kappa$  values were indeed within the range of other recent surveys of the quality of patient information aids using the EQIP instrument.<sup>12,13</sup>

Although this could be culture- or country-specific, the inclusion of an informed consent form in patient decision aids is not recommended according to the EQIP authors.<sup>10</sup> The reason is 2-fold: (1) the addition of a consent form could evoke a certain pressure on the patient to sign it, and (2) a consent form is useless for the patient if there is no discussion with the medical team. A patient is given written information about the procedure, but he or she also has to be informed orally and actively participate in the discussion with the health care provider.<sup>55</sup>

One of the limitations of this study is the use of the English language for searching the Internet, although most people speak English as their first or second language in developed countries.<sup>56</sup> Although LDLT is much more popular in countries with limited access to cadaveric procurement, we surprisingly found only 18 Web sites originating from Japan and China. This suggests that the deficit may be even greater in those areas. Another limitation is the selection of the keywords that were used in various combinations for Internet searching. These keywords were chosen without consultation with any living liver donors. This selection was based only on the assumption of what potential donors would use, and this resulted in the potential for missing some relevant Web sites. Finally,

because the EQIP instrument does not include all the components of the IPDAS checklist, some elements of the international recommendations are not addressed in this study.

In conclusion, our systematic analysis of available Web sites providing information for candidates for LDLT highlights a worrisome lack of informative data, particularly with respect to the risks associated with surgery. Only a few Web sites had high scores according to the EQIP instrument, and they still did not fulfill all the required criteria. Most of these sites originated from specialized societies. We encourage centers performing LDLT to refer patients to information provided by such societies and strongly recommend that the developers of donor aids follow the EQIP criteria. There is an urgent need to produce a Web site that includes comprehensive and well-structured information for LDLT donors and that respects the international recommendations. Our next step then will be the creation of a Web site including all information for living liver donors according to the EQIP instrument and international standards.

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