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Development of a multinational registry of pediatric deceased organ donation activity

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Abstract

Background: There are no currently agreed upon international standards for reporting of pediatric deceased organ donation activity. This leads to difficulty in comparisons between jurisdictions for both researchers and policy stakeholders. The goal of this project was to develop and test a standardized registry for pediatric deceased donation activity.

Methods: Four countries (Canada, Spain, USA, and the UK) with geographical and practice diversity were approached to participate. Iterative exchanges were used to

Abbreviations: DBD, donors (or donation) after brain death; DCD, donors (or donation) after circulatory determination of death; GODT, Global Observatory on Donation and Transplantation; ISHLT, International Society for Heart and Lung Transplantation; NHSBT, National Health Service Blood and Transplant; ONT, Organización Nacional de Trasplantes; pDBD, pediatric donation after brain death; pDCD, pediatric donation after circulatory determination of death; PMP, per million population; SRTR, Scientific Registry of Transplant Recipients; UK, United Kingdom; UNOS, United Network of Organ Sharing; USA, United States of America; WHO, World Health Organization.

create data fields and definitions that were acceptable to all participants. Data from 2011 to 2015 (inclusive) were requested from national health databases and analyzed on a secure, web-based survey platform.

Results: Data were obtained from three of the four countries (Canada unable to provide). Total pediatric donation rates were stable over the 5-year period, but with variation between countries. pDCD rates were the most variable, representing 32.2% of total pediatric donation in the UK, 14.4% in the United States, and 2.6% in Spain during the studied period. Most organs from pediatric donors were allocated to adult recipients, though the rates of allocation of pediatric kidneys to pediatric recipients ranged from 7% in the United States to 40% in Spain.

Discussion: In this limited cohort of three countries, we demonstrated substantial variation in pediatric donation rates and practice. These data highlight opportunities for practice improvement such as the development of rigorous clinical practice guidelines. Future development of this registry will seek to engage more countries, and address barriers that prevented full participation of approached jurisdictions.

1 | BACKGROUND

The WHO and the ONT have created the GODT, which has the mandate to report the "practices, safety, quality, efficacy and epidemiology of transplantations".[1] The GODT serves an important role in collating data from many countries to comparatively track donation and transplantation activity, but at this time it does not provide detailed information on pediatric deceased donation practices. Reporting of pediatric donation and transplantation data varies substantially between jurisdictions, including the four nations we attempted to survey. In the United States, the Organ Procurement and Transplantation Network website[2] allows for analysis of donation data specific to the pediatric age group defined as birth to 18 years of age, but data comparing DBD vs DCD is only available on request. The 2014-2015 UK annual report details the number of DBD and DCD donors[3] but does not report the number or types of organs recovered from these groups of patients, though it is available on request. The Spanish annual report also provides figures on pediatric donation and transplantation activities,[4] with more detailed statistics being available upon request. In addition, these countries use different definitions of pediatric donors and divide the pediatric group into various age ranges. Non-governmental registries such as the ISHLT also collate important data, though they are often designed to evaluate more narrow questions.[5] For example, the ISHLT database is focused exclusively on thoracic organs, not on general pediatric organ donation and transplantation system performance.

This lack of a standardized definition for pediatric donors limits its data acquisition and the ability of researchers and stakeholders to clearly understand pediatric deceased donation performance. For example, Canadian policy makers hope that recently published guidelines on pDCD will result in increased activity in that type of donation and plan to track if this activity could have a negative impact on rates of pDBD donation.[6] Without standard national and international benchmarks for comparison, it will be difficult to determine the impact this initiative has had on the pediatric donation system. Clearly, separating donation rates among standardized age ranges in the pediatric population is also important, since the causes of death in children vary substantially by age. For instance, it would be expected that the ratio of DCD and DBD would be different in the neonatal population, where according to United States data, the most common causes of death are prematurity and congenital anomalies compared with adolescents who most frequently die from traumatic injuries.[7] Developing a better understanding of these differences will allow clinicians, researchers, and policy makers to target resources and researchers to identify knowledge and implementation gaps for donation and transplantation initiatives.

Thus, we aimed to develop standardized reporting of pediatric deceased donation activity that could serve as a basis for the development of an international registry.

2 | METHODS

2.1 | Country selection

Four countries were chosen to participate. Inclusion was based on geographical and practice diversity. Spain was specifically included because of its experience in international data collection, as organization appointed by the WHO to develop and maintain the GODT, and because of its worldwide leadership in deceased donation. The UK is known as world leader in adult controlled DCD practices, the United States has one of the largest centralized databases of donation activity, and Canada is a country with a developing pDCD program. No funding was available for participation which was entirely voluntary and solicited through direct contact of pediatric organ donation leaders in the respective countries.

TABLE 1 Glossary

Term	Definition
Actual donor	A deceased person from whom at least one solid organ has been recovered for the purpose of transplantation
DCD	Donation from a person declared dead by circulatory criteria, following the withdrawal of life-sustaining therapies (controlled) or following an unsuccessfully resuscitated cardiac arrest (uncontrolled). Also referred to as non-heart beating donation or donation after cardiac death
DBD	Donation from a person declared dead by neurologic criteria. Often referred to as donation after neurologic determination of death in North America
Guidelines or protocols	Clinical practice guidelines that govern the practice of deceased donation. Specifically for this survey, this refers to national or regional level protocols/guidelines, not institutional protocols
Hands off time or no touch period	Period of continuous observation of circulatory and respiratory arrest in order to determine the fact of death during which no interventions are taken to prepare the potential donor for organ recovery
Importation and exportation of organs	Transport of organs across national boundaries for the purpose of transplantation
Pediatric donor	A donor under the age of 18 (regardless of age cut-off that the corresponding health care service specifies for pediatric vs adult health care)
pDBD	Pediatric donation after brain death
pDCD	Pediatric donation after circulatory death
Utilized donor	A deceased person from whom at least one solid organ has been transplanted

2.2 | Ethics

This registry requested only aggregate, anonymous data, produced voluntarily by national registries. As such, institutional ethical approval was not required. A data sharing agreement was signed by all participating members.

2.3 | Design of the registry

The data elements incorporated into the registry were agreed upon through iterative exchanges between the authors. Data fields for inclusion were selected by consensus following discussion of perceived importance and potential integration into existing national and international registries. Data were queried from 2011 to 2015. A data dictionary was created to ensure clarity of definitions (see abbreviated version in Table 1). The final full data request given to national registries is available as supplementary material (Appendix S1). Data were collected only for deceased donation activity, and living donation was not considered in this iteration of the registry. The reported age ranges were defined based on consensus among authors with the goal that they most closely corresponded to age ranges in existing registries and data bases.

2.4 | Data collection and verification

The registry data fields were entered into the online survey platform LimeSuvey™, LimeSurvey GmbH, Hamburg, Germany. For Spain and the UK, data were entered directly into the website by staff from the ONT (Spain) or the NHSBT. Both ONT and NHSBT are central, national level organizations responsible for the allocation and coordination of transplantation of all organs offered for recovery in those countries. Information in their databases is routinely updated in real time and has procedures for data verification and audits. US data were obtained through a custom data request with UNOS. Data from UNOS are collected within the SRTR and from ongoing collection from hospitals, organ donation organizations, and immunology laboratories. These organizations are mandated to report to the SRTR, which in turn is mandated to collect publicly available data on all donation and transplantation activity within the United States. These data are regularly validated and cross referenced. Data obtained from UNOS were entered manually into the registry by Canadian Blood Services staff (MG and NL). Canadian data were requested from the Canadian Institute of Health Information through their Canadian Organ Replacement Registry, though not obtained. Summary tables were prepared by Canadian Blood Services staff and reviewed by all authors. Data were validated by all authors, with potential discrepancies reviewed in the source data.

2.5 | Population estimates

UK population counts by age were derived from a publicly available population estimate for the UK from mid-2016.[8] US and Spanish populations by age category were estimated from demographic pyramids reproduced on the basis of data from the US Census Bureau[9] and the Spanish National Statistics Institute,[10] respectively. UK and Spanish populations are based on mid-2016 estimates, while US populations are based on mid-2015 estimates because the equivalent 2016 data were not available. Canadian population estimates were not sought out due to difficulty in obtaining study data.

2.6 | Statistics

Because of the small number of participating countries, data were reported using only descriptive statistics. No between or within country comparisons were performed.

3 | RESULTS

Administrators at the Canadian Institute of Health information had concerns about the confidentiality implications of public reporting of low frequency events, defined by them as tables with cells containing fewer than five patients. This resulted in Canadian data that were provided in a way that prohibited integration into the registry. Other options, such as attempting to collect the data from the provincial organ donation organizations individually, were met with similar resistance, such as a lack of clarity if provincial data sharing agreements would allow sharing of this data for research purposes. Considering the certainty that pursuing these options would result in intolerable delays and uncertain chances of success, the possibility of obtaining useful Canadian data was abandoned for this iteration of the registry. Thus, the results and tables represent the data submitted by Spain, the UK, and the USA only.

Figure 1 demonstrates the trend in the number of total pediatric DBD and DCD donations over time. Currently, all pDCD activity practiced in the surveyed countries is controlled DCD (or after a planned withdrawal of life-sustaining therapy) as opposed to uncontrolled DCD, where DCD procedures take place immediately after a failed resuscitation. While there was variability in total numbers, there was no obvious trend towards an increase or decrease over time in total pediatric donation numbers in any of the countries. pDCD as a percentage of total activity remained nearly constant for all three countries, though variable between countries (Figure 2). On average, over the 5-year period, pDCD represented 32.2% (74/231) of total pediatric donation in the UK, 14.3% (608/4244) in the United States, and 2.4% (5/205) in Spain. With so little variability in the rate of pDCD compared to total pediatric donation, there was no discernible impact on total pediatric donation activity, though in the UK, the 1 year that pDCD fell below 30% of total pediatric donation (2012) was the year with the fewest number of total donors.

Table 2 shows the number of actual donors for 2015 indexed PMP divided by age group. The only age group to have a PMP donation rate approaching the adult population in that country were children under 1 year in the United States in the DBD pathway. All other age groups and donor types had donation rates well below the adult rates, and most under five PMP.

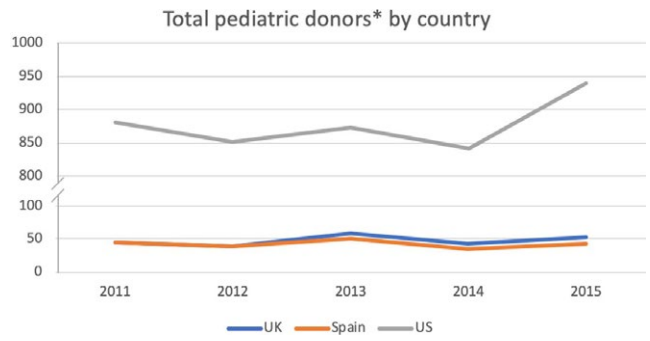

FIGURE 1 Total actual pediatric donors by country*. *A deceased person from whom at least one solid organ has been recovered for the purpose of transplantation

The organs transplanted per donor table (Table 3) shows that in the United States and Spain the trend was for more organs to be recovered per donor as the donors grew older. That trend was not the case in the UK where they reported 6 and 6.5 organs per donor for their pDBD donors of <1 and 1-5 years, respectively. These results included only two donors in each of those age groups. The transplanted organs from the two patients who became donors under 1 year of age included heart, liver, bowel, pancreas, and en bloc kidneys from one donor and liver, two kidneys, pancreas, heart, and

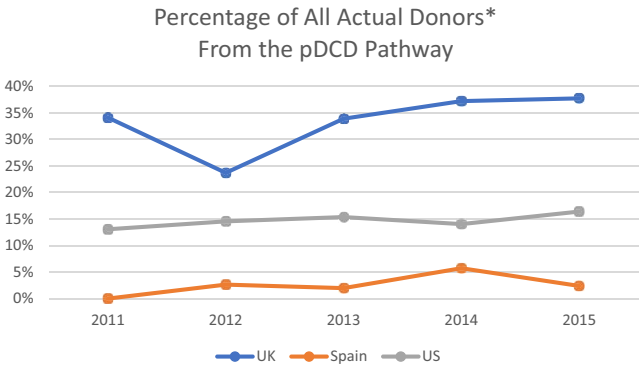

FIGURE 2 Percentage of all actual donors* from the pDCD pathway. *A deceased person from whom at least one solid organ has been recovered for the purpose of transplantation

TABLE 2 2015 Donors: actual donor counts PMP per age group

	2015 actual		
	Spain	UK	US
DBD			
Pediatric			
<1 y	4.9	2.6	29.5
1-5 y	6.2	0.5	10.9
6-10 y	2.8	1.8	5.2
11-17 y	5.7	4.3	11.8
Peds total	4.9	2.4	10.7
Adult (≥18 y)	39.1	14.1	27.4
DBD total (adult and peds)	33.0	11.6	23.6
DCD			
Pediatric			
<1 y	0.0	7.7	8.0
1-5 y	0.0	0.5	1.4
6-10 y	0.0	1.0	0.9
11-17 y	0.3	1.6	2.6
Peds total	0.1	1.4	2.1
Adult (≥18 y)	8.2	10.2	5.4
DCD total (adult and peds)	6.7	8.3	4.6
All donations	39.8	20.0	28.2

PMP counts are based on population estimates for each age group from sources mentioned above.

two lungs from the other. Across countries, pDCD organ recovery from small children resulted in few organs per donor, with the United States and the UK both reporting averages of two or fewer organs until the age of 6 years. All countries reported more average organs recovered per donor (DCD and DBD) in their pediatric than adult donor populations.

Organ allocation was also examined to determine if organs recovered from pediatric donors were more likely to be transplanted in adult or pediatric recipients. While there was some variability by jurisdiction, with the exception of the heart, all organs in all jurisdictions were more likely to be allocated to adult recipients. In the United States, 7% (113/1619) of kidneys (pDCD and DBD) recovered from pediatric donors in 2015 were allocated to pediatric recipients. The same year 39.3% (26/66) of all pediatric recovered kidneys were transplanted into pediatric recipients in Spain. pDCD kidneys were even less likely to be transplanted into pediatric recipients, with the UK reporting 6.1% (2/33) of pDCD recovered kidneys transplanted into pediatric recipients and the United States and Spain reporting 3.5% (9/266) and 0% (0/2), respectively.

Pediatric hearts were more likely to be transplanted into pediatric recipients in all jurisdictions. No country reported a pediatric heart recovery using the pDCD pathway during the study time period, though three neonatal pDCD hearts were previously reported in the United States in 2008,[11] and a recent report from the ISHLT registry reported 4 pDCD heart transplants from 2010 to 2014, though that paper did not mention in which country those transplants occurred.[12]

There was very little import or export activity for any of the survey countries Appendix S2.

TABLE 3 Organ transplants per donor (2015)

	Actual		
	Spain	UK	US[a]
DBD			
Pediatric			
Neonatal (≤30 d)	–	–	
1 mo-1 y	3.0	6.0	2.8
1-5 y	3.2	6.5	3.6
6-10 y	3.6	4.7	3.8
11-17 y	4.1	5.3	4.8
Peds total	3.7	5.3	4.0
Adult (≥18 y)	2.5	3.3	3.2
DBD total	2.6	3.4	3.3
DCD			
Pediatric			
Neonatal (≤30 d)	–	2.0	–
1 mo-1 y	–	2.7	1.8
1-5 y	–	2.0	1.7
6-10 y	–	4.3	2.1
11-17 y	2.0	4.4	2.5
Peds total	2.0	3.5	2.1
Adult (≥18 y)	1.7	2.2	1.9
DCD total	1.7	2.3	1.9
All donations	2.4	2.9	3.0

[a]United States did not report neonatal transplants separately. For the purposes of this table neonatal donors and resulting transplants we combined into the <1 y strata. (US only).

3.1 | Barriers and facilitators to registry development

The most significant barrier encountered during the development of this registry was the inability to collect complete data from one of the four countries surveyed. This was primarily due to interpretations of privacy laws and data sharing agreements as discussed above. Future extension of an international registry will have to account for those considerations, including how to publicly report rare events that lead to small numbers of patients in each cell.

4 | DISCUSSION

Our findings demonstrate it is possible to create a multinational registry of standardized data representing pediatric deceased donation activity. Our research represents the first stage in the creation of international pediatric-focused benchmarks that can be used to evaluate the performance of deceased donation systems and provide the information required by policy makers to target areas for quality improvement and researchers to identify knowledge gaps.

A clear conclusion from the data contained in this registry is that pediatric deceased donation is a rare event. Donation rates PMP were far lower than adult rates in all jurisdictions for all types of donation. Considering low pediatric mortality rates compared to adults, this is not unexpected. In this pilot registry, country-specific mortality rates were not included in our calculations. However, it is well known that both mortality rates and cause of death vary significantly by age. In the United States in 2014, the mortality rate under 1 year was 24.5 times higher than that in the 1- to 4-year age group.[13] While Spain was able to provide detailed mortality reports for this project, since we could not compile corresponding data from the other countries, we excluded mortality rates from the current analysis. Detailed reports of mortality rates and cause by age group will be important to incorporate in future iterations of this registry.

pDCD rates were particularly low, and while variable by jurisdiction, stability in each jurisdiction over the years observed. For example, in Spain there was only one pDCD donor in 2015, in the 11- to 17-year-old age range (0.1 donor PMP). Conversely, in the United States, there were 2.1 pDCD donors PMP, with DCD donors recorded in all age ranges including neonates. Of note, controlled pDCD was only piloted in 2009-2011 and introduced into the Spanish system in 2012. Though the rate of controlled DCD in Spain rose rapidly to 17% of total donors and 70% of total DCD activity in 2015,[14] it had not

been systematically incorporated into pediatric practice as of 2015. Controlled DCD is an established part of the British and American overall donation systems, representing 10.9% in the United States[15] and 40% in the UK[3] of total donation (adult and pediatric) in 2015. This is an example of the importance of an international registry to highlight differences in system performance in order to drive research hypothesis generation and practice change. While our data cannot suggest a causal link, it is possible the acceptance of DCD in the overall system played a role in increasing the number of pDCD cases. Other structural factors could merit future investigation into why some systems have different rates of pDCD compared to pDBD, such as if the fact that the UK utilizes a brain stem as opposed to the whole brain definition of brain death employed in the United States plays any role. Whatever the cause of the described variable pDCD rates, it will be important for stakeholders to explore means of improving pDCD performance. The role of DCD implementation in driving increases in donation activity has been well documented in the adult donation literature,[14,16] and the data from this registry suggest potential for improvement in pediatric practice.

Another practice difference noted in our registry was in the allocation of pediatric organs. Previous reports from the United States indicate that the majority of organs recovered from pediatric donors are allocated to adults.[17] There are many factors contributing to the preferential allocation to adults. There are more adult recipients waiting for organs, and size and weight constraints pose issues for pediatric recipients. In our data, while all countries allocated the majority of pediatric recovered kidneys to adult recipients, the rates of pediatric kidneys allocated to pediatric recipients varied from 7% to 40%. Rates of allocation to pediatric patients of pDCD recovered kidneys were low, but also variable from 0% to 6.1%. This variability offers an important opportunity to evaluate the effectiveness of these allocation decisions. For example, pediatric priority exists in most kidney allocation systems, so children receive organ offers more quickly than adult wait list candidates. This priority, combined with the need for pediatric recipients to receive an organ with excellent longevity, allows pediatric programs to wait for the best possible offer.[18] This may mean result in programs refusing a pDCD kidney due to real or perceived issues with organ quality. Further investigation into outcomes of pediatric recipients of pDCD kidneys from countries where this more routinely occurs will help inform future algorithm generation.

Overall pediatric donation activity was relatively unchanged during the 5 years of data collection. This was true for both pDBD and pDCD activity. A recent report from Australia[19] showed similarly stable rates of pDBD per PICU deaths over a 15-year period (2000-2015). This report captured an uptake of pDCD donors with implementation starting in 2006. A recent report from the Transplantation Society Ethics Committee emphasized the need for more robust evidence-based tools in pediatric deceased donation.[20] While some such guidelines have been published since,[6] there remains a dearth of evidence-based guidance for how to best identify and manage patients who are potential organ donors. As identified in recent literature reviews,[21,22] this is due to a variety of factors, including the lack of research in this vulnerable population. A standard, international registry will allow stakeholders to identify areas of system performance variability. In doing so, researchers will be better able to identify clinically relevant questions to investigate, donation system administrators will be able to focus quality improvement resources, guideline development groups will be able to identify knowledge translation gaps, and clinicians will be better informed on how to maximize the rare opportunities of pediatric organ donation. Ultimately, these changes will positively affect the two most important stakeholder groups: families of patients who are potential donors and the patients waiting to receive donated organs. While some of these improvements are possible through local initiatives, all of them could be accelerated through data and practice sharing of these rare events across jurisdictions.

There are numerous limitations to the data included in this registry. The most significant barrier to development of the registry was inability to obtain and report data from the Canadian national health care database because of privacy concerns around reports of infrequent events. Concerns over confidentiality are of clear importance, but this concern must be weighed against the potential societal benefit of improved performance in the organ donation and transplantation system. Any future attempts to expand this type of registry will require upfront, clear agreements for data sharing with the organizations responsible for storing data, so that a timely transfer of data is possible. This risk might be mitigated if the data collection of this registry was incorporated into a pre-existing international registry, such as the GODT. Another limitation is the absence of living donation data from the registry. While the emphasis on this version of the registry is deceased donation, the impact of living donor rates on pediatric recipients will be an important issue to explore in future iterations.

Statistical analysis of the estimates PMP was generated based on reported national statistics. As previously described, these population estimates did not always correspond to our reported age ranges, forcing us to estimate populations for some age categories. Time and resource limitations prevented us from obtaining more accurate population data for this report, but future iterations of this registry will be based on more detailed population estimates from the reporting countries. Similarly, future iterations will benefit from being indexed to country-specific mortality rates, which will allow for further refinement of comparisons. Further improvements could include estimates based on PICU and NICU mortality as shown in the recent Australian report.[19] It would be expected that pediatric mortality rates would be variable between countries and would certainly vary between age groups. Our plan is to ensure that resources are in place for future iterations of this registry that would allow the collection and validation of mortality data in the included countries. Ultimately, the data would be most useful in the form of a standardized potential donor audit where deaths of all children who could have become donors (eg, all deaths of ventilated patients) are reviewed. While these mechanisms have been shown to be important components of high functioning donation systems,[23] implementation considerations will require balancing the resources necessary

to harmonize data collection and reporting across countries with the benefit gained from more granular data.

Finally, further consideration of the scope of the registry will need to be clarified with participating countries. The issue of transplant outcomes is of particular interest. Since the goal of donation is always successful transplantation, having a measure of short- and long-term patient and graft outcomes would be highly informative in this type of registry. However, several barriers will remain, including the fact that transplant outcome data may represent further logistic and privacy barriers. Recipient outcome data are not always stored in the same registries as donor data, and researchers attempting to link these datasets in a Canadian context[24] have experienced substantial resistance related to perceived privacy concerns. The goal would be to continue to convince stakeholders who control access to this information that the potential gains from more robust data collection could be done without sacrificing patient confidentiality.

Through this registry of surveyed countries, we demonstrated pediatric deceased donation continues to be a relatively rare event, though one that is highly impactful to the health care system, families of patients who were potential or actual donors, and patients waiting for an organ transplant. Only by learning from our performance in an open, transparent manner will we be able to ameliorate the system. As this registry attempts to recruit more participating countries, it will be important to clarify potential barriers caused by data sharing legislation prior to incorporation of data from new countries into the database. The logistics of housing such a database will also need to be determined. Possible fusion of this data collection with extant databases, such as the well-established GODT run by the WHO would be a possible solution that would prevent the creation of duplicate data collection while also benefiting from a robust, existing infrastructure.

5 | CONCLUSION

This project demonstrated international collaboration to share pediatric deceased donation data can be accomplished, though not without difficulties. Despite limitations of the current data, identification of important practice variations between countries can serve as a source of hypothesis generation for donation researchers and policy makers. As future iterations are established, it will be important to expand our understanding of country-specific mortality rates and ensure that all countries can fully share data related to these uncommon but impactful events.

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AUTHORS' CONTRIBUTIONS

Matthew J. Weiss: Lead author, responsible for study idea, design, data collection, manuscript drafting and editing; Nick Lahaie, and Meagan Green: Responsible for data collection, database management, data analysis; All authors: Responsible for study design, data validation, manuscript editing and approval.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of the article.

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