Curr Pediatr Res 2016; 20 (1&2): 176-182 *ISSN 0971-9032*
www.currentpediatrics.com

Religion and life support withdrawal in children: What do healthcare providers wish?

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Abstract

Objective: To study the relationship of faith with hypothetical life support withdrawal decisions for their own children among healthcare providers.

Design: We created a 33 questions survey named "End of Life Questionnaire" We surveyed 858 healthcare providers and staff of 9 healthcare institutions in the United States, Mexico and Panama. The main outcome measure was willingness to withdraw medical care even if this contradicted a religious edict. Statistics were mainly descriptive.

Results: The study included 180 doctors [21%], 317 nurses [36.9%], and 354 other healthcare institution workers [41.2%]. Most 57% [n=489] had children. Of the responders [51.9%, n=445] denoted themselves as Catholic. On a scale of 1-5 [1 being not spiritual and 5 being very spiritual], 39.6% defined themselves as very spiritual, 51% somewhat spiritual and 6.5% not spiritual. An association was found between having children and willingness to withdraw care even if this contradicted a religious edict [p=0.036]. Those who had children, 23% [114/483] would withdraw care, and respondents without children, 17.6% [63/357] would withdraw care [p=0.040]. This association was strong in non-doctor, non-nurse staff members [among those with children 26.6% [50/188] would withdraw care vs. among those without children 15.5% [26/168], p=0.013]]. In contrast, among medical-professionals, there was no association between having children, and willingness to withdraw care for their child. Responder gender was not associated with willingness to withdraw care.

Conclusion: Professional perspectives overshadowed the emotional influence of parenthood when workers of healthcare institutions made decisions regarding withdrawal of life support for their own child against a religious edict. Non-medical professionals were more willing to withdraw care if contradicted with their religion.

Keywords: Child, Nurse, Care.

Accepted August 27, 2016

Introduction

Since 1990 the number of deaths among children <5 years old has almost halved globally [from 12.7 million [95% Confidence Interval [CI] 12.5, 12.9] in 1990 to 6.3 million [95% CI 6.1,6.7] in 2013] [1]. Even within the United States, which often represents medical care in the developed world, childhood mortality has decreased from 11/1,000 live births to 8/1,000 live births during the last two decades [1]. While on the one hand many pediatric deaths are potentially preventable with appropriate medical therapy, this may also mean that most pediatric deaths that do occur in high income countries may in fact be unavoidable. Such deaths usually occur after heroic lifesaving efforts have been implemented [2].

A recent survey published by the Collaborative Pediatric Critical Care Research Network demonstrated that most deaths in PICUs occurred after life support has been limited or withdrawn [3]. Withdrawal of life-support treatment in children has only recently begun to receive attention in the medical literature, mainly from the perspective of the family of the child [4]. However, healthcare workers are responsible

for providing support to the family of the child, when making such decisions to withdraw life-support [5]. When making treatment decisions regarding infants and children, the risks implicit in the chosen treatment, the likelihood of a favorable outcome, the amount of pain and/or discomfort this therapy entails, the psychological impact on the child and the family, and the future quality of life of the child, need all be considered [6]. Yet studies regarding withdrawal of life support in adults show that the value judgments and personal preferences of the treating staff may alter the information presented to the family, as well as the ability of the healthcare provider to provide support when a withdrawal decision is made [7,8].

To best of our knowledge, the attitudes of healthcare workers towards withdrawal of life support in children have never been studied. We set out to study the willingness of healthcare providers to withdraw care for their own child. We also sought to understand whether individual attitudes are associated with religion and spirituality, as well as the role of the healthcare worker within the system [i.e., whether healthcare workers who are directly involved in patient care differ from those that constitute the supportive logistical framework of the hospital].

Methods

We performed a cross-sectional survey of preferences among the staff working in nine health care institutions [hospitals and small clinics] in the United States, Mexico and Panama.

Questionnaire Preparation

The dedicated questionnaire was constructed during a series of meetings between medical students, an expert in critical care and a hospital pastor. The questions underwent content and expert validity testing by additional experts in critical care, neonatal care and pediatrics [who work in and outside the United States], prior to finalizing the questionnaire which consisted of 33 items, all surveys questions were closed. The data collected included respondent demographics [e.g. sex, marital and parental status, profession] as well as religion, degree of religiosity, faith tradition limitations and questions addressing their willingness to withdraw care for a child.

Survey Methods

The survey was conducted by 15 medical students practicing and studying in the three countries being surveyed. The choice of institution was based on convenience and availability. All the students underwent group training in survey methods prior to participating in the study as surveyors.

In order to ensure that all the healthcare workers within the participating institutions would be approached, the principal investigator received permission from the hospital directors for participation of their staff in the survey and shortly thereafter also received from the human resources department of each hospital a list of the staff and shifts. This list was turned over to the interviewers, thus ensuring that both day and night shift workers would be approached.

Prior to participating in the survey, respondents were informed that their willingness to participate was voluntary and anonymous, that the questionnaire will not include their details and that the list of participants would not be transferred to the hospital administration. In order to ensure that the participants understood the survey questions, the questionnaire was offered in either English or Spanish [after undergoing validated back translation]. All the questionnaires were self-administered and participants were requested to avoid addressing the students during questionnaire completion. The main outcome was not provided to the respondents in order to avoid any bias. Completed questionnaires were returned to the students on location without respondent identifying details.

Statistical Analysis

The main outcome measure was the proportion of healthcare providers who would be willing to withdraw care for their child. The secondary outcome measure was to characterize these healthcare providers [e.g. religion and spirituality, role within the healthcare system]

All data was inserted into a dedicated SPSS database [SPSS Statistics for Windows, Version 21.0, released 2011, Armonk, NY: IBM Corp.] A questionnaire was considered complete and included in the analysis if $\geq$ 90% of the questions were answered. Descriptive statistics [i.e., proportions, percents, means and standard deviations, ranges, medians and interquantile ranges] were first employed for studying the population. Logistic regression analysis was used to study the association between respondent characteristics and personal preferences, and the dichotomous response to the question “Would you withdraw treatment for your child if it contradicted what your faith/tradition allows?" In the first step univariable analysis was used. Variables found to have a significant overall association with the likelihood of a positive response were included in the multivariable model. The odds ratio (or) of a positive response with the 90% confidence interval for the OR and the p-value of this association were tabulated.

Results

A total of 851 questionnaires were completed by healthcare providers and healthcare workers. There was a similar proportion of single and married responders [39.9% [n=342] and 41.5% [n=356]]. Most respondents [57%, n=479] had children.

Nurses constituted the greatest professional sector among the respondents [36.9%, n=317] and almost half of them [47.3%, n=150] had experience working in an Intensive Care Unit. A fifth of the respondents were physicians [21%, n=180]. Internal Medicine doctors [23%, n=42] predominated within this group of healthcare practitioners. There were also quite a few respondents who were Emergency Medicine doctors [14.4%, n=26], General practitioners [13.8%, n=25] and Anesthesiologists [4.4%, n=8]. The rest of the cohort was comprised of medical students [10.5%, n=90], bio-technicians [5.7%, n=49], patient care assistants [4.3%, n=37], pharmacists [1.3%, n=12] and additional health care workers including case managers, psychologists, housekeeping, culinary staff, dentists, nutritionists and even security staff [overall 167 other healthcare staff] (Table 1).

Table 1: *Participant demographic characteristics, overall 858 participants completed the survey questionnaire*

Characteristics		N	%
Gender	Male	320	37.3%
Marital status	Married	356	41.5%
	Single	342	39.9%
	Divorced	60	7.0%
	Common law	70	8.2%
	Widowed	18	2.1%
	Other	11	1.3%
Parental status	Have children	489	57%
Religious practice	Practicing member of a religion	315	36.7%
	Non-practicing believer	373	43.5%
	Spiritual but not religious	115	13.4
	Atheist	44	5.1%
Faith/tradition	Catholic	445	51.9%
	Christian	209	24.4%
	Protestant	27	3.1%
	Jehovas witness	15	1.7%
	Buddhist	14	1.6%
	Moslem	13	1.5%
	Hindu	11	1.3%
	Mormon	8	0.9%
	Jewish	6	0.7%
	Other	65	7.6%

Within the cohort as a whole, 36.7% [n=315] defined themselves as practicing members of a religion [i.e., active in their religious traditions and tend to follow most of the practices and beliefs dictated by their religion], 43.5% [n=373] defined themselves as non-practicing believers and only 5.1% [n=44] defined themselves as atheists. Most respondents defined their religion as Christian [76.1%, n=653]. Among these, most [68.1%, n=445] were Catholics. On a Likert scale ranging between 1 [not spiritual] to 5 [very spiritual], most respondents considered themselves either very spiritual [39.7%, n=340] or somewhat spiritual [51%, n=438] and only a minority viewed themselves as not spiritual [6.5%, n=56].

Willingness to withdraw life support for a child: Among all the survey participants one in five [20.6%, n=177] stated that they would be willing to withdraw treatment for their own child even if this act contradicted the accepted practice of their religious belief. The more the healthcare worker considered themselves spiritual, the greater their willingness to withdraw care for their child regardless of the edicts of their faith/ tradition (Figure 1).

Univariable analysis demonstrated that healthcare workers that have children and are not medical doctors or students were more willing to withdraw care. Healthcare workers in the United States also tended to withdraw care more than their colleagues in Mexico and Panama. Christian healthcare workers demonstrated greater reluctance to withdraw care than non- Christian healthcare workers. Finally, healthcare workers who preferred not to undergo resuscitation themselves were more willing to withdraw care for their child as well. All of these respondent characteristics remained significant in the multivariable analysis, except for country of medical practice (Table 2).

Discussion

The current study shows that one in five healthcare workers would be willing to withdraw medical care for their own child regardless of religious restrictions. Parental status and lesser medical education are associated with willingness to uphold such decisions as well as the perceptions of the individual regarding their own spirituality. Most interesting was the association we found with personal resuscitation preferences; healthcare workers that preferred not to undergo resuscitation themselves tended to be more willing withdraw care for their child.

To the best of our knowledge, there is limited literature regarding the attitudes of diverse healthcare workers regarding withholding and withdrawal of pediatric life support and even less regarding the association of these attitudes with their end-of-life preferences. Our study encompassed a relatively large number of respondents. We included healthcare workers with diverse professions from multiple national, cultural and work environments. Because of their workload and often unconventional working hours, healthcare workers are difficult population to survey. We used the traditional method, personally handing out paper forms to achieve a greater response rate, when surveying these hard-to-reach respondents. The surveys were conducted anonymously, in order to encourage candid responses.

In his controversial yet signature work "Centuries of Childhood", the historian Philippe Aries claims that societal perception of childhood as a distinct phase of life evolved only in the late 15th century [9]. Until recently, pediatric mortality was so high that parenting was mostly emotionally detached and adults were considered of much greater value than children. No attempt was made to protect children for the hardships of life and many were exploited because the high likelihood of an early death was a given. In many cultures human rights were bestowed only after entering adolescence and children were often gifted with a name only after surviving to a certain age [9]. Modern Western culture has embraced a more romantic view of children as humans possessing natural abilities and intuition which remain unscathed by culture and morals which have yet to be corrupted by civilization [10]. This has led to current perceptions that the life of a child is more valuable even than life of an adult, making the attempt to preserve the life of a child at any cost a social norm. Hand in hand with this perception decreasing pediatric mortality supports the belief that losing a child is a particularly painful experience.

Decisions regarding withholding and withdrawal of pediatric life support are usually undertaken a medical environment, creating a situation whereupon healthcare providers of all types may constitute the support system for the parents. The decision-making process is not driven by clinical guidelines, formulas or algorithms. Despite the recommendations describing best practices for some aspects, variability in

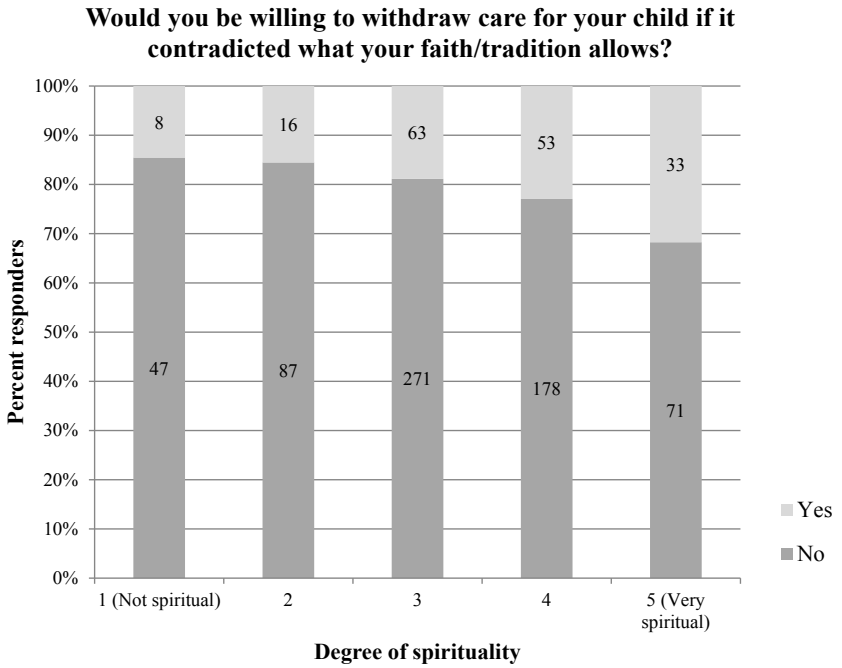

Figure 1. *Degree of spirituality and willingness to withdraw care even this contradicts the decrees of the faith/tradition being followed*

Table 2. *Association between respondent characteristics and personal resuscitation preferences, and response to the question; would you withdraw treatment for your child if it contradicted what your faith/tradition allows?*

Variable	Category	% response "Yes" (n)	Univariable analysis		Multivariable analysis	
			OR (95% CI)	p-value	OR (95% CI)	p-value
Sex	Male (reference)	23% (73/318)	reference	---	Not in the model	---
	Female	19.6% (104/531)	1.223 (0.872, 1.715)	0.242		
Parental status	No children	17.6% (63/357)	reference	---	---	---
	Children	23.6% (n=114/483)	1,442 (1.022, 2.033)	0.037	1.527 (1.014, 2.300)	0.043
Profession	Doctors	14.1% (25/177)	reference	---	---	---
	Nurses	24.3% (76/313)	1.950 (1.188, 3.201)	0.051	1.934 (1.110, 3.368)	0.020
	Other hospital workers	23.1% (61/264)	1.827 (1.096, 3.045)	0.252	1.873 (1.052, 3.333)	0.033
	Medical students	14.1% (13/90)	1.026 (0.498, 2.118)	0.119	1.826 (0.822, 4.053)	0.139
	Overall	---	---	0.017	---	0.114
Degree of spirituality	1	14.5% (8/55)	reference	---	---	---
	2	15.5% (16/103)	1.080 (0.431, 2.711)	0.869	1.866 (0.645, 5.402)	0.250
	3	18.9% (63/334)	1.366 (0.615, 3.034)	0.444	2.036 (0.781, 5.310)	0.146
	4	22.9% (53/231)	1.749 (0.778, 3.932)	0.176	2.455 (0.927, 6.502)	0.071
	5	31.7% (33/104)	2.731 (1.160, 6.426)	0.021	3.446 (1.237, 9.603)	0.018
	Overall	---	---	<0.001	---	0.123
Religion	Christian (Any type)	19.3% (130/675)	reference	---	---	---
	Non-Christian (Any type)	27.2% (46/169)	0.638 (0.432, 0.941)	0.023	0.580 (0.371, 0.907)	0.017

Country	Mexico	16.2% (53/328)	reference	---		
	Panama	22.3% (25/112)	1.491 (0.875, 2.541)	0.142	1.730 (.933, 3.210)	0.082
	United States	24.2% (99/409)	1.657 (1.143, 2.401)	0.008	1.376 (0.885, 2.140)	0.157
	Overall	---	---	0.027	---	0.171
Have you discussed your code status with your health care provider?	No	19.8% (125/631)	reference	---	Not in the model	---
	Yes	23.5% (51/217)	1.244 (0.859, 1.800)	0.248		
What is your present code status	Definitely full code	19.9% 98/493	reference	---	---	---
	Full pharmacologic support but no intubation or chest compressions	16.9% (10/59)	0.823 (0.402, 1.682)	0.592	0.875 (0.410, 1.867)	0.731
	I have never thought about it	18.5% (33/178)	0.917 (0.592,1.421)	0.699	0.940 (0.582, 1.516)	0.799
	Definitely no code	40.0% (24/60)	2.687 (1.532, 4.713)	0.001	2.334 (1.277,4.264)	0.006
	Overall	---	---	0.003	---	0.036
* Missing responses: sex 9, parental status 18, profession 14, degree of spirituality 31, religion 14, country 9, code status discussion 10						

end-of-life practice has been documented among continents, countries and cities [11]. It is time-consuming and often emotionally draining; personal opinions are often varied and no two clinical scenarios are the same [12].

Several authors have described the importance of involvement of healthcare providers in end-of-life care in pediatric patients. In 90% of the cases physicians are the first to discuss discontinuation of life-support, and nurses brought up the topic in the rest of the cases [10%] [13]. The advice and attitudes of hospital staff other than non-nurses or physicians and the advice of family members and friends are often taken into consideration by those making the decision [13].

The decision to withdraw life-support is undoubtedly a challenge for any parent. In addition to the emotional ramifications of this situation, there are the ethical and legal complexities of terminating treatment for a human who is incapable and/or lacks the right to voice their opinion regarding their own end-of-life. Parents required to undertake decisions regarding withholding or withdrawal of medical care, may find themselves conflicted between their wish to adhere to the principles of beneficience and nonmaleficience [e.g. alleviate the suffering of their child] and the need to follow cultural/religious value judgments [e.g. the demands of their religion] and the best interests of the family [14]. Professional literature [e.g. the Royal College of Paediatrics and Child Health practice recommendations] emphasizes not only the legal and medical aspects of adhering to the benefit of the child, but also the importance of respecting parental religious preference [15]. Religion and spirituality confer a significant amount of support [16]. In a study conducted in 3 Pediatric ICUs in Boston using open ended questions, Robinson et al. surveyed parents who decided to withdraw life support for their children [n=56]. Almost three quarters of the responders [73%] claimed that spiritual/religious themes had given them the greatest amount of support; "prayer, faith, access to and care from clergy, and belief in the transcendent quality of the parent-child relationship that endures beyond death" [14]. In our study, only a minority of respondents expressed willingness to go against religious restrictions if required to withdraw medical care for their own child. Possible explanations may be a fervent "belief in miracles" but this may lead to conflict with the medical team and parental neglect of the best interest of the child [16].

Terminal illness is often accompanied by a significant amount of suffering. Patients, families and healthcare providers all agree that symptom control is a major contributor to a good death [17]. Despite this the decision to withhold or withdraw life-sustaining treatment for children often precedes death by several hours only [18]. In a study performed on 275 children's who died in PICUs, they found that over two thirds [68%] of deaths occurred after support was limited or withdrawn, with minimal variability observed across sites, finding this percentage similar to other recent reports from PICUs in North America, northern Europe and Australia. [3]. Last decisions may be associated with performance of unnecessary invasive and painful procedures [19]. Performance of inappropriate medical procedures for a child facing a poor prognosis can be often prevented with early discussion and provision of appropriate explanation [20]. Timely discussion of end-of-life issues enables initiation of palliative care and provides a sufficient amount of time for the family to discuss their preferences, thus improving the quality of life for both family and the patient [21,22]. Parents that have undertaken a life support withdrawal decision for their child seem to have a better understanding of the child's medical condition [23].

The American Academy of Pediatrics clinical guideline recommends involvement of the child in the decision to forgo

with life sustaining treatment [24]. We did not address this issue in our survey. Surveys with closed-ended questions have a lower validity rate than other survey types. We chose this method to allow us to survey a greater number of people. Our survey did not encompass all of the healthcare workers of the surveyed medical facilities. This may have introduced bias into our sample. In order to maintain respondent anonymity and avoid questions regarding compliance, once the survey was done the checklists of potential participants had to be shredded.

Conclusion

Healthcare staffs constitute the support structure for parental decisions regarding withdrawal of care. Professional experience and knowledge regarding prognosis and end-of-life care should exert a predominant influence on the attitudes of healthcare providers regarding withdrawal of pediatric life support. In this study we demonstrate that these may conflict with their own religion and personal preferences. Further study needs to focus on the methods of reconciling this internal struggle, allowing healthcare to focus on the needs of the child and parents under their care, regardless of their personal value judgments.

Acknowledgement

We would like to offer a very special thank you for the selfless help of the students who helped with the implementation of the survey, another thank you to the different institutions, hospitals and clinics that opened their doors to us, and a last one to Father Rafael who guided with his knowledge in theology in the design of the of the spirituality questions.

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