

Exploring societal solidarity in the context of extreme prematurity

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Summary

QUESTION: Extreme prematurity can result in long-term disabilities. Its impact on society is often not taken into account and deemed controversial. Our study examined attitudes of the Swiss population regarding extreme prematurity and people's perspectives regarding the question of solidarity with disabled people.

METHODS: We conducted a nationwide representative anonymous telephone survey with 1210 Swiss residents aged 18 years or older. We asked how people estimate their own personal solidarity, the solidarity of their social environment and the solidarity across the country with disabled persons. Spearman's correlation calculations were used to assess if a correlation exists between solidarity and setting financial limits to intensive care and between solidarity and withholding neonatal intensive care.

RESULTS: According to 36.0% of the respondents intensive medical care should not be withheld from extremely preterm infants, even if their chances for an acceptable quality of life were poor. For 28.8%, intensive care should be withheld from these infants, and 26.9% held an intermediate position depending on the situation. A total of 31.5% were against setting a financial limit to treatment of extremely preterm newborns with an uncertain future quality of life, 34.2% were in favour and 26.9% were deliberating. A majority (88.8%) considered their solidarity toward disabled people as substantial; the solidarity of their personal environment and of the society at large was estimated as high by 79.1% and 48.6%, respectively.

CONCLUSIONS: The Swiss population expressed a high level of solidarity which may alleviate some pressure on parents and health care providers in the decision-making process in neonatal intensive care units. In addition, there was no relationship between solidarity and people's willingness to pay for the care or withholding treatment of extremely preterm babies.

Key words: extreme prematurity; population survey; solidarity; disability; resource allocation; Switzerland

Introduction

Over the last decades, new treatment options have led to a decrease in mortality for extremely preterm infants. However, long-term morbidity has not yet decreased accordingly [1, 2]. It is often difficult to predict which infants will die and which will survive with long-term disabilities. This medical and moral uncertainty complicates decision-making between parents and healthcare providers [3]. In this respect, the burdens for babies, families and healthcare professionals have frequently been studied, yet the impact on society is often not taken into account and deemed controversial. In fact, decisions do not only

have developmental, psychological and emotional repercussions for extremely preterm infants and their families, but they also have an impact on society [4].

Providing care for infants at the limit of viability is one of the most expensive healthcare interventions [5, 6]. But in spite of these high costs, neonatal intensive care units (NICUs) are remarkably cost effective [7, 8]. In addition, surviving extremely preterm babies and their families often report a good quality of life (QoL), comparable to that of babies born at term [9, 10]. But discussions on resource allocation for infants born too early continue. Healthcare resources are limited and the question is how to fairly distribute limited resources amongst a patient population in light of long-term outcomes [11].

High individual costs, cost effectiveness and resource allocation play a complex role in decision making for extremely preterm infants. Besides immediate care, parents may also consider society's acceptance and assistance much later in life when formerly extremely preterm infants with a moderate or severe disability may need continuous treatment and financial support [12, 13]. In this context, social cohesion as perceived by parents may influence choices about life-sustaining treatment. Societal solidarity, however, depends highly on the given circumstances of a country. Solidarity toward disabled people can identify the willingness to carry the costs for extremely preterm infants at risk for disabilities.

We aimed, by means of a population survey, to understand how people in different linguistic parts of Switzerland estimate their own personal solidarity, the solidarity of their social environment and the solidarity across the country toward disabled persons. We also intended to analyse the relationship between solidarity and setting an upper limit to neonatal intensive care costs, and between solidarity and withholding intensive care for infants born extremely prematurely.

Methods

Study design

We conducted a population-based telephone survey among Swiss residents on their opinions and values regarding extremely preterm infants. The questionnaire was prepared in German and translated into French and Italian. The translation accuracy was checked by back-translation into German and simultaneous review by a panel of translators to ensure identical semantic content in each language.

At the beginning of the interview, respondents were informed that our study concentrated on "extremely preterm infants", which meant infants born before 28 weeks of gestation – before 7 months of pregnancy with a birth weight often ranging between 600 and 800 grams. It was also clarified that these infants always require intensive care treatment.

The survey consisted of 16 questions with mean interview duration of 13.8 minutes (95% confidence interval 13.5–14.0 min). Themes that are explored in this article pertain to: (1) perceptions regarding extreme prematurity; (2) views on intensive care measures; and (3) assessment of the solidarity with disabled persons. Conventional sociodemographic information was collected on gender, age, residency, education and income level, as well as importance of religion, personal experience with prematurity and whether participants had children.

Data collection

We recruited people living in Switzerland who were aged 18 years and older through random allocation drawn from the official telephone registry. Quotas were allocated for linguistic regions (German, French, and Italian), age and gender in order to allow for generalisation across the whole population. The market and social research institute gfs-zurich conducted the survey. Participants were informed about the study and procedures for anonymity. Respondents had the opportunity to withdraw from the survey at any time point. As this anonymous population survey did not include any patient data or health-related data of the participating persons, the Ethics Committee of the Canton Zurich did not require formal ethical approval.

Data analyses

Statistical analysis was performed using IBM SPSS Statistics 22 (Armonk, NY, USA). The quota from the Italian-speaking part was increased in order to have a sufficient number of answers for comparisons with the other linguistic areas. All cases were weighted to adjust for this stratification. Thus, the percentages presented cannot be derived from the absolute unweighted numbers in the tables. Groups (age, gender, linguistic region, importance of religion, level of education) were compared using a z-test or a t-test with Bonferroni adjustment for multiple comparisons where appropriate. Linear regression analysis to test for the independent effect of these factors was considered but discarded, since this would have meant use of weighted data, in which case the proportion from the Italian-speaking part would have been too small to detect any differences. A p-value <0.05 was considered statistically significant. Solidarity was assessed with a 5-point Likert scale. These responses were grouped into two adjacent categories in the text for ease of interpretation: high (somewhat or much higher estimation) or not high (average or lower estimation). Spearman's correlation calculations were used to assess if a correlation exists between solidarity and setting financial limits to intensive care, and between solidarity and withholding intensive care treatments.

Results

Characteristics of the respondents

A total of 1210 adults living in Switzerland completed the telephone survey, yielding a 23.7% response rate. Most respondents were aged between 40 and 64 years (45%) and had children (70%). Two thirds (68%) did not have previous experience with prematurity personally or in their social surrounding (extended family and/or friends). Five per cent of respondents were parents of a premature infant and 26% knew parents of a preterm infant in their close social environment. Religious faith was reported to be stronger in the German (54.1%) and Italian regions (53.3%) as opposed to the French region (41.6%). The main characteristics of our respondents are summarised in table 1.

Extreme prematurity and intensive care

In general, people's associations with extreme prematurity were very diverse. The most common impressions were linked to notions such as

fighting for survival (11%), future consequences (9%), incubators (9%), giving them a chance (7%) and small infants (7%). Fewer answers addressed emotions ($\leq 4\%$: pity, hope, fear, burden) or the QoL and disabilities ($\leq 3\%$).

The majority of our respondents (67.1%) estimated that the use of highly specialised medicine for these extremely preterm infants would be supported in Switzerland. A smaller number (20.8%) thought intensive care would not be endorsed, and 12.1% did not know.

For 36.0%, intensive medical care should not be withheld from extremely preterm infants, even if their chances for an acceptable QoL were poor. For the same situation, 28.8% thought intensive care should be withheld from these infants, 26.9% held an intermediate position depending on the individual situation, and 8.3% did not know. Regional differences were found. More respondents from the French-speaking part of Switzerland (39.3%) agreed to withhold treatment as opposed to the German-speaking (25.9%) and the Italian-speaking (18.5%) regions ($p < 0.001$).

An upper financial limit for treating extremely preterm infants with an uncertain future QoL was considered justified by 34.2% of respondents. Another third (31.5%) considered such a financial limit as unacceptable, another 26.9% took an intermediate view, and 7.4% could not answer the question. Higher educated people (42.9%) were more often against an upper financial limit than people with a medium (28.0%, $p = 0.003$) or lower (25.3%, $p < 0.001$) level education. People who considered that intensive care treatment should be withheld from extremely preterm infants with an expected poor QoL more often agreed to set financial limits to intensive care, as shown by a weak correlation ($r = 0.125$, $p < 0.001$; table 2).

Characteristic	%	n	
Gender	Male	49.7	602
	Female	50.3	608
Region	German part	72.0	707
	French part	24.0	303
	Italian part	4.0	200
Age	≤ 39 years	35.0	423
	40–64 years	45.0	544
	≥ 65 years	20.1	243
Having own children	Yes	70.2	837
	No	29.8	373
Personal experience with prematurity	Weak	68.2	831
	Strong	31.5	375
	Missing	–	4
Importance of religion	Not important	48.9	586
	Important	51.1	606
	Missing	–	18
Education	Low	7.2	99
	Middle	66.1	805
	High	26.6	297
	Missing	–	9
Monthly income (CHF)	≤ 4000	13.8	176
	4001–7000	34.2	399
	7001–11000	25.9	308
	> 11000	11.9	134
	Missing	–	193

Total n = 1210. Percentages without missing values unless indicated.
* Regions are based on: the German speaking part, the French speaking part and the Italian speaking part of Switzerland. All results in % are weighted for region, numbers of respondents (n) are unweighted.

Table 2: Correlations between withholding treatment, setting an upper financial limit, and solidarity.

		Medical interventions should be withheld when prospective outcome is poor.	An upper financial limit for intensive care is justifiable.	My solidarity towards disabled people is substantial.	The solidarity towards disabled people in my personal environment is substantial.	The solidarity towards disabled people in Switzerland is substantial.
Medical interventions should be withheld when prospective outcome is poor.	r		0.125	-0.054	-0.060	0.016
	p		<0.001	0.104	0.070	0.627
	n		1042	1107	1082	1082
An upper financial limit for intensive care is justifiable.	r	0.125		0.000	-0.020	0.112
	p	<0.001		0.991	0.551	0.001
	n	1042		1114	1087	1095
My solidarity towards disabled people is substantial.	r	-0.054	0.000		0.517	0.162
	p	0.104	0.991		<0.001	<0.001
	n	1107	1114		1171	1174
The solidarity towards disabled people in my personal environment is substantial.	r	-0.060	-0.020	0.517		0.322
	p	0.070	0.551	<0.001		<0.001
	n	1082	1087	1171		1149
The solidarity towards disabled people in Switzerland is substantial.	r	0.016	0.112	0.162	0.322	
	p	0.627	0.001	<0.001	<0.001	
	n	1082	1095	1174	1149	

Spearman's correlation coefficients are shown. Results are weighted for region, numbers of respondents (n) are unweighted. For exact questions and answer categories, see the appendix that you will find as PDF file on www.smw.ch.

Table 3: Evaluation of solidarity.

Do you agree with the following statements?	1 completely disagree		2		3 agree partially		4		5 completely agree		Do not know	
	%	n	%	n	%	n	%	n	%	n	%	n
	My solidarity towards disabled people is substantial.	0.7	7	1.1	13	8.7	103	32.5	404	56.4	676	0.6
The solidarity towards disabled people in my personal environment is substantial.	1.2	14	2.3	28	14.5	187	33.5	415	45.6	530	2.9	36
The solidarity towards disabled people in Switzerland is substantial.	2.6	32	9.5	104	37.1	427	28.8	360	19.7	256	2.2	31

Total n = 1210. All results in % are weighted for region, numbers of respondents (n) are unweighted.

Self-rated and estimated solidarity with disabled people

The population's perception toward solidarity for people with disabilities was explored. We asked respondents to estimate their own solidarity, the solidarity in their personal environment (i.e., family and friends), and finally the solidarity within the Swiss population. Overall, 88.9% of respondents expressed substantial solidarity towards disabled people. People also considered the solidarity of their social environment as high (79.1% of respondents). Solidarity towards disabled people in Switzerland was felt to be substantial by 48.5% of our sample (table 3). The estimation of one's own personal solidarity was influenced by several sociodemographic factors. Respondents with a strong affiliation to religious faith more often considered their solidarity with disability as substantial (63.1%), in contrast to people without a religious affiliation (49.3%, $p < 0.001$). Likewise, parents (62.7%) rated their personal solidarity higher than non-parents (41.6%, $p < 0.001$). The same held true for people residing in the German-speaking region (60.7%) who rated their personal solidarity higher than people from the French-speaking area (45.6%, $p < 0.001$). For 58.5% of the respondents the willingness of society to support disabled people had improved over the last 10 years. A smaller group (25.7%) held the view that the support has remained constant, whereas 10.2% considered it has deteriorated.

Spearman's correlation analyses revealed no correlation between people's self-rated solidarity towards disabled persons and rejecting the possibility to withhold intensive care treatment in cases with poor prognosis (table 2). In addition, no correlation was found between respondents' estimations of their personal solidarity and setting financial limits for the treatment of extremely preterm infants. Similarly,

solidarity of the respondents' social environment also did not show any of the above-mentioned correlations. People who found an upper financial limit for treatment justified, rated solidarity toward disabled persons in Switzerland as more important, although this correlation was weak ($r = 0.112$, $p = 0.001$).

Discussion

This is the first nationwide study in Switzerland, and the largest representative report, to analyse public perceptions and values toward extreme prematurity [14]. Our major finding is that the Swiss population expressed a high overall solidarity with disabled persons. Interestingly, there was a clear difference between the personal, social environmental and societal level of solidarity. Swiss people rated their personal solidarity as very high, whereas solidarity in their social surrounding and in the general society was perceived as lower. This could be caused by the fact that people are better at estimating their own valuations as opposed to those of the society. Conversely, response and social desirability bias could also have caused these differences. Furthermore, we found that people who considered it justifiable to withdraw care for babies born extremely preterm with expected poor QoL outcomes were also more inclined to set economic limits to intensive care for this group of patients. However, those people who found financial limits justified estimated that the solidarity in Switzerland was high.

We can only speculate on the reasons for such high solidarity. On the one hand, this might portray a commitment to a fair distribution of healthcare resources. Despite the need for resource allocation and setting financial limits, it is possible to do so fairly while still protect-

ing the health interests and needs of the weakest members of society. On the other hand, it might illustrate the limited role financial and economic factors play in people's self-rated solidarity toward weaker groups in society. The motivation of individuals to support health care and social protection has mainly focused on financial aspects; however, these considerations may be also influenced by elements of compassion, commonality and mutuality [15]. This can go beyond economic considerations [16]. Instead it might be the common ground between individuals from which mutual obligations arise to help and support each other when necessary [17]. Hence, our study indicates that solidarity does not merely reflect the commitment of a group to carry the financial costs.

Another factor that might explain the high level of solidarity people emphasised is the resemblance of the vulnerability of disabled patients such as former extremely preterm infants. It is known that solidarity is strongest with those people or groups that strike us as noteworthy and with whom we share a resemblance [17, 18]. The extreme vulnerability of extremely preterm infants and their acute need for life-sustaining care could foster a connection of resemblance [19]. Additionally, these infants cannot be held responsible for the medical decisions that have taken place either prior to their birth (i.e., decisions to initiate/withhold treatment) or after birth (e.g., continuing/withdrawing life-sustaining therapy).

Finally, the context of the Swiss healthcare system could have supported the right conditions for a high level of solidarity. The Swiss healthcare system is thought to reflect an egalitarian sentiment where solidarity plays an important role in public discourse. In addition, the health system and the current social health insurance system are greatly valued by patients and the population as a whole [20, 21]. Hence, solidarity is something that is shaped within a society over time and can vary in different contexts [18]. This is also apparent in other countries where resource allocation decisions are based on medical facts as well as societal values [22].

The geographic variation within Switzerland raises the question as to whether there is an explanation based on factors such as religion, age, sex and socioeconomic status. Age and gender were evenly distributed among the linguistic regions as our survey was designed to be representative for these variables. The importance of religion varied between the linguistic areas, being strongest in the German- and Italian-speaking regions. Income and education were correlated and were higher in the German part. However, our analyses do not indicate that the geographic variation would be due to the differences observed in importance of religion or socioeconomic status.

Our findings potentially impact on parents' decision making in the context of extreme prematurity. One study on parental decision-making preferences has suggested that the level of societal support and financial difficulties could be aspects that influence parents' decisions [12]. Another study investigating what could influence parents' decisions to limit or withdraw life support has pointed out that personal finances and societal limitations in healthcare resources are a concern for parents [13]. Despite national policies specifying that economic considerations should not interfere with ethical decision-making in individual cases [23, 24], clinical reality shows that sometimes issues unrelated to the child's well-being, such as social acceptance and support, may influence decision making [12, 13, 25]. Under these circumstances, parents, together with the healthcare team, must make decisions about the appropriateness of life-prolonging intensive care. However, assessments of societal support and solidarity will become more important with recent calls for a sustainable health system [21]. Resource allocation has many inherent ethical concerns that are beyond the scope of this paper [26–28], but, of relevance to this discussion, the more a healthcare system redistributes resources to the members of the collective, the more it is suggested to be an articulation of solidarity [15, 16].

Our study has several limitations. A general limitation of a telephone interview is that it does not allow in-depth exploration, and both questions and responses are limited in their complexity. Despite the required brevity of telephone interviews, several open questions were asked on perspectives concerning extremely preterm infants and minimal criteria for an acceptable QoL. Furthermore, our respondents were categorised into one of the three language areas according to their current area of residence. This raises the question whether some respondents were born and raised in or simply moved into their current area of residence. A further limitation of our study includes the

complexity of the notion of solidarity. As a result of the time constraints of a telephone survey, solidarity could not be clearly defined to respondents prior to the survey. Therefore, it is most likely that respondents may have understood only the most general notion of the term.

Limitations notwithstanding, our nationwide representative sample extends our limited knowledge of the societal solidarity for infants born extremely premature. Methodologically, our response rate was common for a telephone survey of the population on healthcare topics using quota sampling. Our study sample was representative of the demographic distribution of Switzerland as portrayed by the Federal Statistics Office. Therefore, our findings can be generalised to the whole population, thereby allowing a conclusion on how the Swiss population perceives extreme prematurity, and on how end-of-life decisions should be taken for this patient group. Future work should further analyse the validity of solidarity and take into account the limitations encountered in our work. Also, the relationship between solidarity and economic factors should be extended and should include an investigation of the link with social and emotional acceptance and support [16].

Conclusion

Our survey evaluated the societal attitudes toward people living with disabilities in the context of extreme prematurity. Caring for a disabled person always implies the use of health care resources and is directly linked to societal solidarity and support. According to our study, the populations' high level of solidarity toward disabled people goes beyond the financial focus often taken when assessing solidarity. This knowledge is of paramount importance in the ongoing societal discussion on allocation of healthcare resources. Even more importantly, a high societal cohesion toward disabled persons may alleviate some pressure on parents in the decision-making process regarding their extremely premature infant in the NICU.

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Competing interests

The authors have no conflicts of interest to disclose.

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