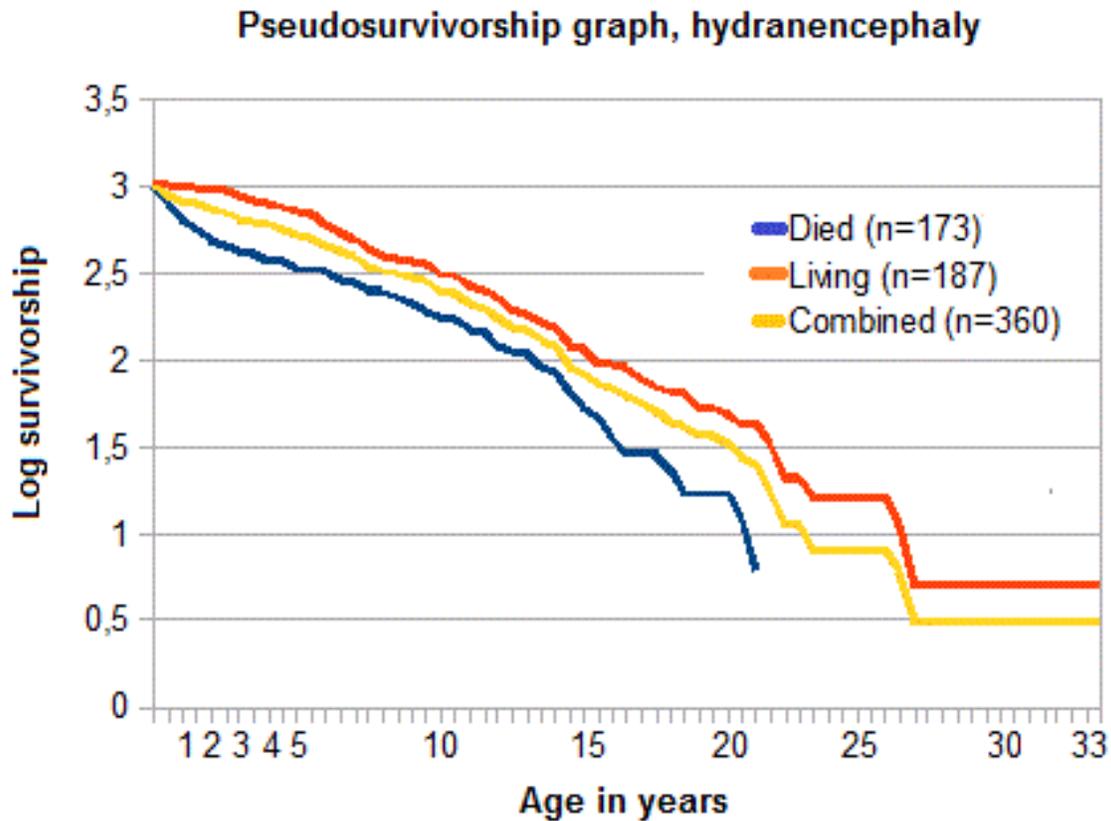


Survivorship in Hydranencephaly



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This graph was made from our database of children with Hydranencephaly. There are 360 children represented in this graph. The first one that Bjorn refers to which was published in Clinical Neurology and Neurosurgery, used only the children who had died up to that time. This graph includes all children whose families had provided information on their child.

Explanation from Bjorn:

As expected it shows the same pattern as in the earlier smaller dataset that was published in Clinical Neurology and Neurosurgery (Type II survivorship curve, which means that a rather fixed percentage of kids die in each successive time interval), but there is an interesting twist to it. I did the whole calculation three times, for the kids that had died, the ones that were living at the time the data were compiled, and the combined population of all of them (360 kids). It

stands to reason that the ones that are all angels lived a bit farther back in time than those now living, statistically speaking, and I was curious whether this difference in time would show up in the graphs.

And it does: look at the top left parts of the curves (up to about 5 years of age) – the orange one (living) has its concavity downwards, the dark blue one (those that have died) has its concavity upwards. That means that among the kids living earlier in time there was more infant mortality in the first few years, then after about age five the curves start running in parallel, which means no difference in the rate of mortality. (The jaggedness of the curves in the lower right means little, it is simply an effect of the fact that there are few long survivals, so the jaggedness is caused by the few cases at that end of the curves).

There may be a very simple (though hypothetical) reason for this difference in the top left part of the curves: It may be accounted for by an improvement over time in the care of the children, with the net effect of reducing early infant mortality. Earlier shunting, feeding tubes, and seizure control among other things may account for the difference, and in this Barb's group may have had a significant impact by giving parents the courage to insist on quality care. The explanation is admittedly hypothetical, but it will be a nice thing to mention in the discussion section of the paper.