Supplement S3. Communication Preferences

|  |  |
| --- | --- |
| Overall |  |
| n | 56 |
| *What is your preferred language to communicate medical information (%)* | n (%) |
| English | 49 (88) |
| Spanish | 7 (12) |
| *I prefer that the CVICU team communicate with me regarding daily care plans (%)* |  |
| I prefer more detail-oriented communication | 30 (54) |
| I prefer big picture communication | 20 (36) |
| I prefer updates from daily rounds | 34 (61) |
| I prefer weekly care conferences | 5 (9) |
| I prefer that providers represent multiple points of view | 10 (18) |
| I prefer that providers give me fewer opinions | 0 (0) |
| Unknown | 4 (7) |
| *I prefer that the CVICU team communicate with me regarding difficult decisions or setbacks in my child s care (%)* |  |
| I prefer more detail-oriented communication | 35 (62) |
| I prefer big picture communication | 19 (34) |
| I prefer updates from daily rounds | 27 (48) |
| I prefer weekly care conferences | 2 (4) |
| I prefer that providers represent multiple points of view | 13 (23) |
| I prefer that providers give me fewer opinions | 1 (2) |
| I prefer including an additional team that specializes in communication | 9 (16) |
| Unknown | 4 (7) |
| *I prefer that the CVICU team communicate with my child regarding daily care plans (%)* |  |
| Speaking directly to my child | 11 (20) |
| Speaking directly to me and I will communicate with my child | 14 (25) |
| I prefer to communicate with my child but would appreciate help regarding developmentally appropriate ways to communicate medical information with my child | 15 (27) |
| I prefer that my child is not directly involved in daily care plans | 4 (7) |
| Not applicable | 17 (30) |
| Unknown | 4 (7) |
| *I prefer that the CVICU team communicate with my child regarding difficult decisions or setbacks in my child’s care (%)* |  |
| Speaking directly to my child | 7 (12) |
| Speaking directly to me and I will communicate with my child | 18 (32) |
| I prefer to communicate with my child but would appreciate help regarding developmentally appropriate ways to communicate medical information with my child | 16 (29) |
| I prefer that my child is not directly involved in daily care plans | 2 (4) |
| Not applicable | 18 (32) |
| Unknown | 4 (7) |
| *In regards to communicating with the medical team (%)* |  |
| I understand the discussion on daily rounds | 36 (64) |
| I do not understand the discussion on daily rounds | 3 (5) |
| I am comfortable discussing my child’s care with the medical team. This includes asking questions and voicing my concerns. | 38 (68) |
| I am not comfortable discussing my child’s care with the medical team | 1 (2) |
| Unknown | 3 (5) |
| *How can the medical team best support you when it comes to making decisions about your child’s care (%)* |  |
| I prefer the medical team tell me the available options and we decide together what is best for my child | 24 (43) |
| I prefer the medical team tell me the available options and their recommendation for what is best for my child | 38 (68) |
| I prefer assistance from a team that specializes in helping parents families through the decision making process | 7 (12) |
| Unknown | 3 (5) |
| *My expectation for my child’s hospitalization is (%)* |  |
| For my child to return home from this illness or surgery in the same or improved condition than before | 44 (79) |
| For my child to return home or rehabilitation center likely requiring ongoing medical care, e.g. home nursing | 7 (12) |
| For my child to receive surgery during this hospitalization | 11 (20) |
| I’m not sure what my goals are | 1 (2) |
| Other | 2 (4) |
| Unknown | 4 (7) |
| *Was this survey worthwhile to complete (%)* |  |
| No | 2 (4) |
| Yes | 48 (86) |
| Unknown | 6 (11) |