

# Discharge Readiness Among Parents of Stage 1 Palliation Infants Participating in a Home Monitoring Program

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## Background

- Hypoplastic Left Heart Syndrome (HLHS) accounts for 2-3% of all congenital heart disease (CHD)
- Staged single ventricle palliation has become the mainstay of therapy at most centers providing care to infants with HLHS
- Despite improving surgical survival rates, infants with HLHS remain vulnerable to even mild changes in physiological state following stage 1 palliation (S1P) discharge
- Mortality during the interstage period (time between S1P and stage 2 palliation (S2P)) is cited as high as 20%
- Our center utilizes home monitoring strategies to detect physiologic changes that may indicate declining clinical status during the interstage period
- The Home Monitoring Program (HMP), first described at Children's Hospital of Wisconsin (CHW) in 2000 includes:
  - Recording of daily oxygen saturations (SpO<sub>2</sub>), weight, and 24 hour enteral intake
  - Weekly phone calls from HMP team
  - Minimum of biweekly clinic visits
- Criteria requiring notification to HMP team includes:
  - SpO<sub>2</sub> <75% or >90%
  - Weight loss of 30g or failure to gain 20g over 3 days
  - Enteral intake of <100cc/kg/day
- In preparation for participation in the HMP, extensive parental training and education is provided by the Nurse Practitioner (NP) members of the HMP team prior to discharge

## Purpose

To assess parental competency and discharge readiness related to participation in an interstage HMP for infants discharged following S1P for HLHS

## Methods

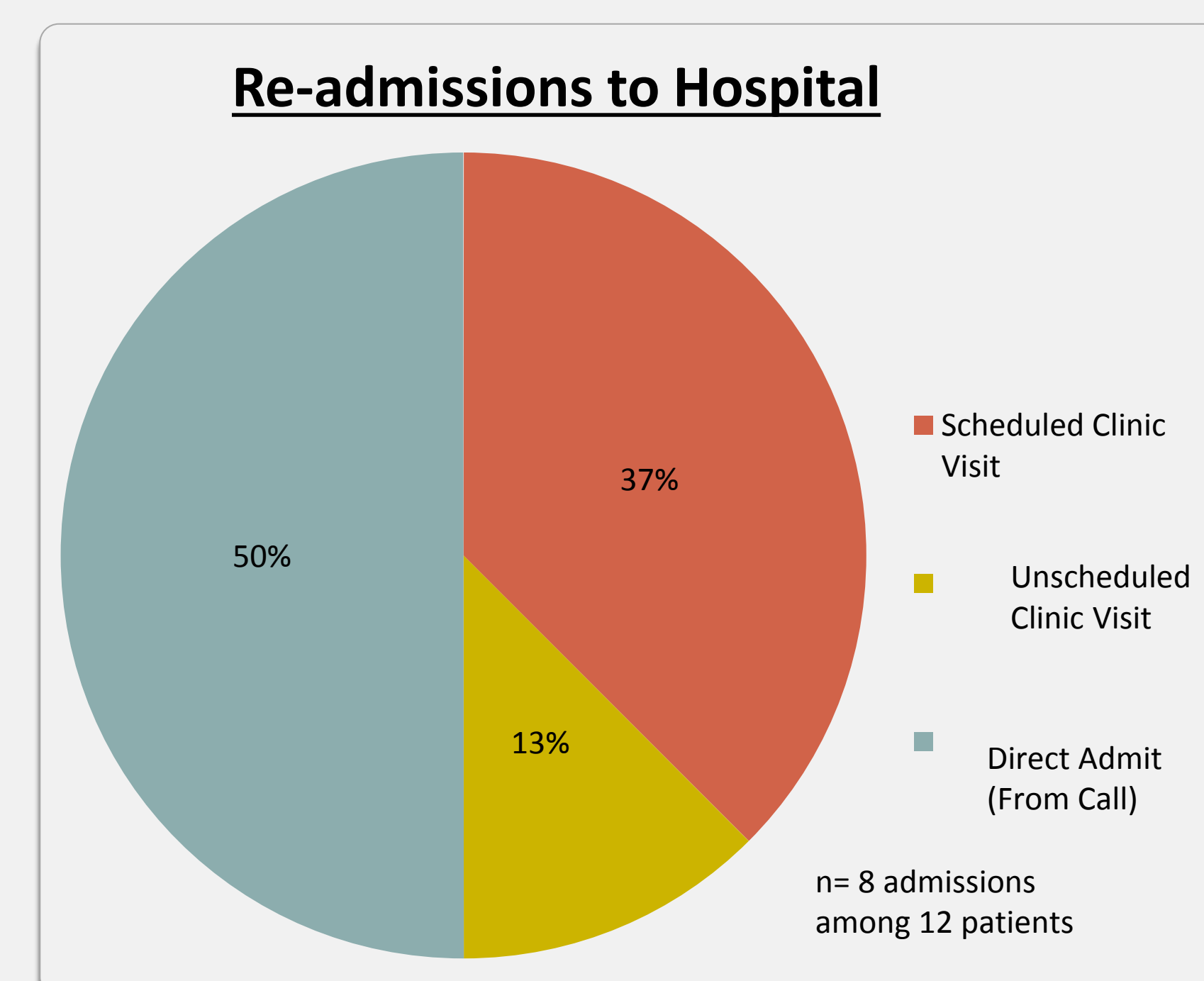
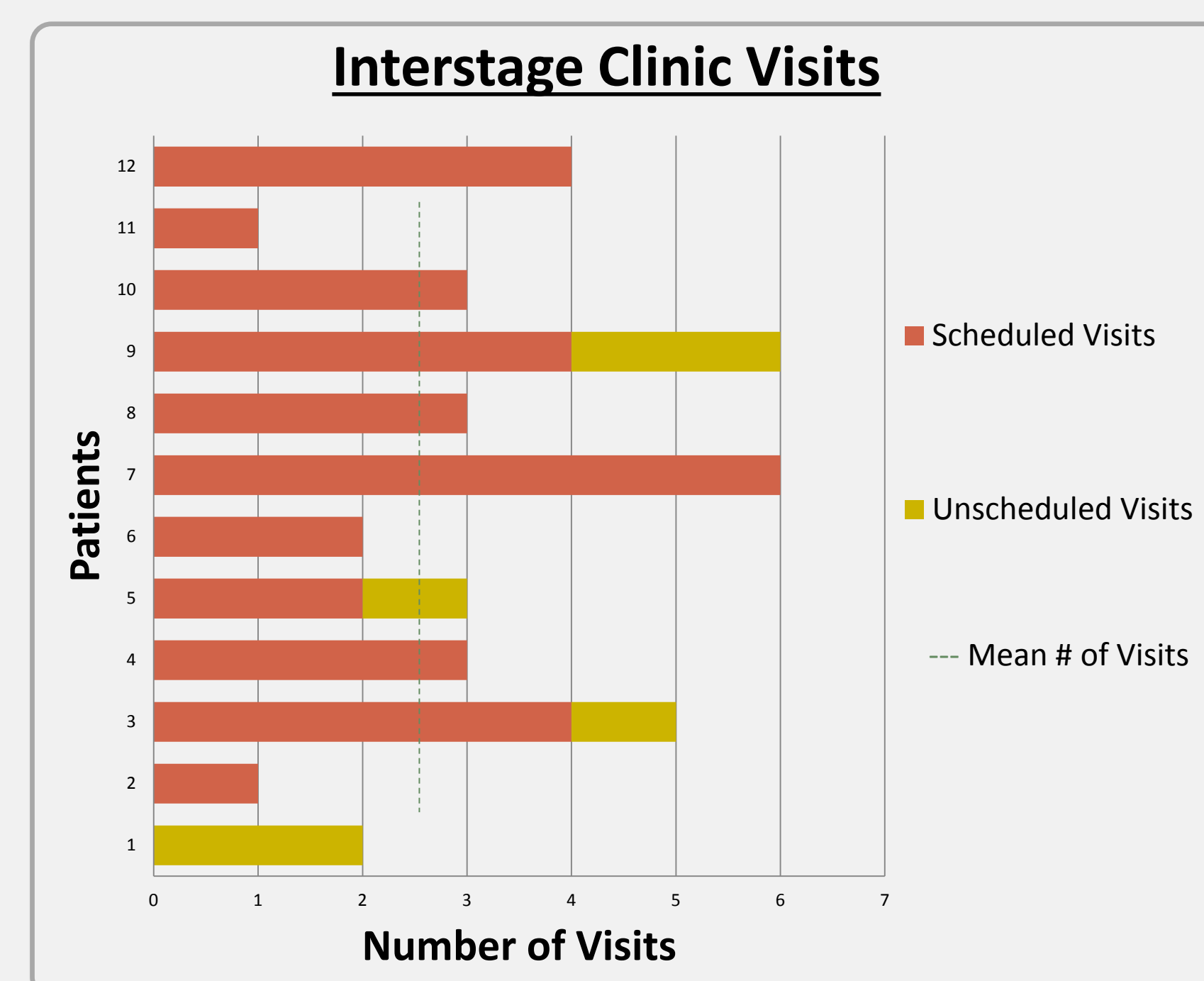
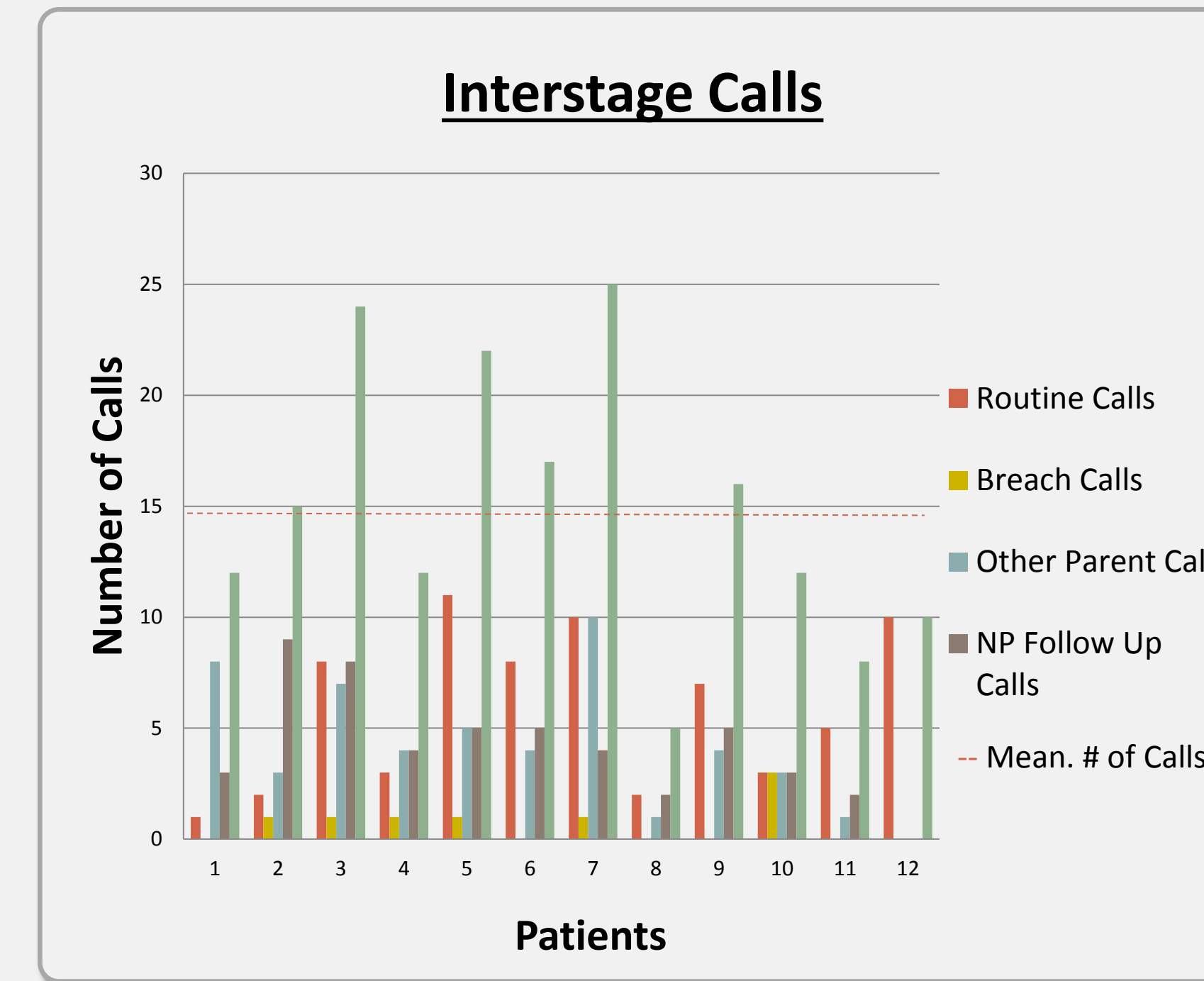
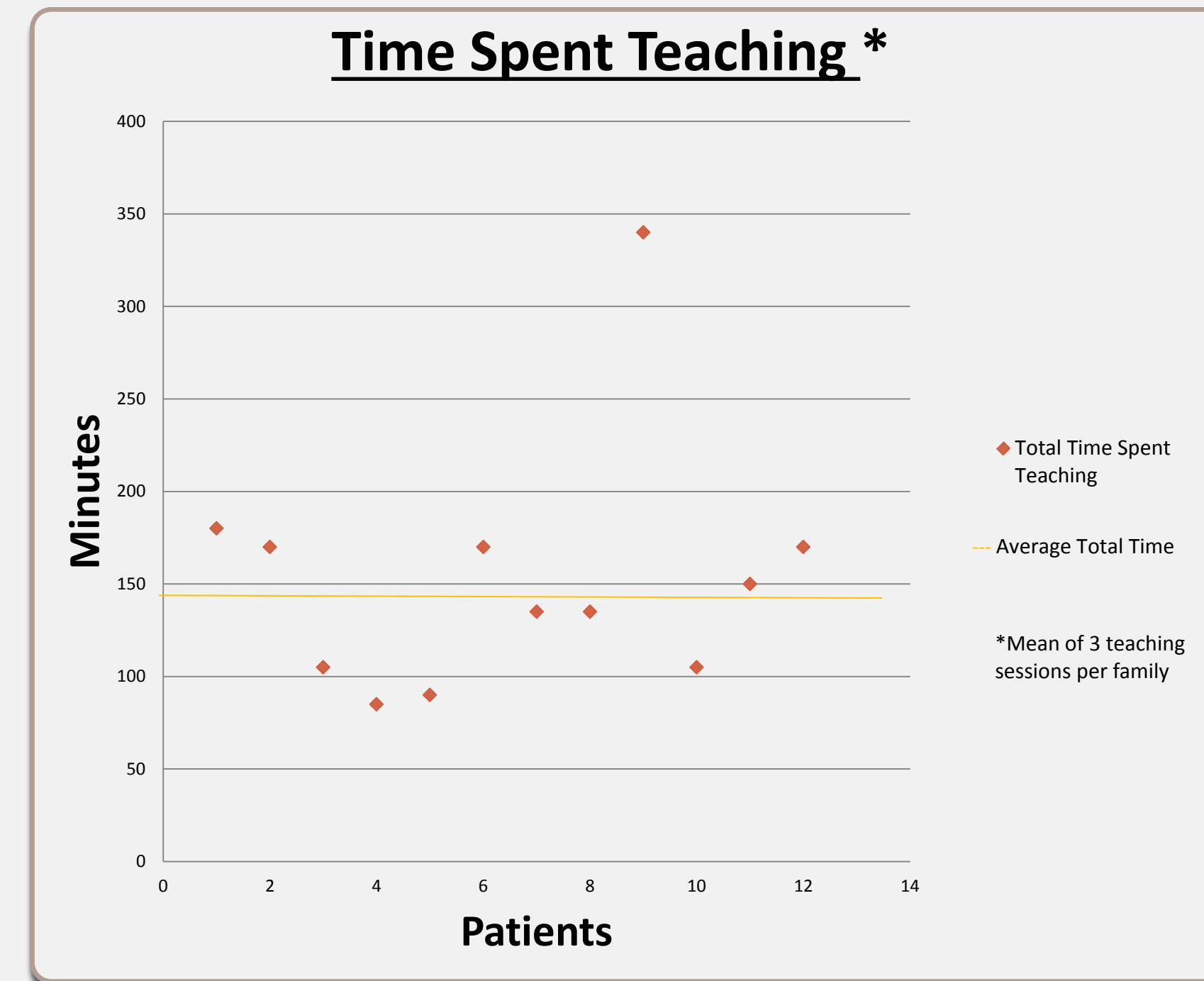
**Population:** Data analyzed for 12 consecutive infants discharged into CHW HMP between October 2011 and November 2012

### Data Collected:

- Inpatient data: Teaching sessions (quantity and total time spent)
- Outpatient data: Duration of interstage period, number of phone calls, clinic visits (scheduled/unscheduled), and unplanned re-admissions
- Parent Questionnaire: Hard copy given at first interstage clinic visit, subsequently entered into Survey Monkey



## Results



## Parent Questionnaire Results

	Strongly Agree	Agree	No Opinion	Disagree	Strongly Disagree	No Response
Purpose and detail of HMP were adequately explained	11 (91.7%)	1 (8.3%)	—	—	—	—
At discharge I understood the reasons for concern that required me to contact the home monitoring team and how to reach them	12 (100%)	—	—	—	—	—
Contents and organization of the home monitoring binder were useful to me	8 (66.7%)	4 (33.3%)	—	—	—	—
Teaching on how to operate the scale/pulse oximeter and in-hospital support provided by the Nurse Practitioners adequately prepared me for home monitoring after discharge	8 (66.7%)	3 (25%)	—	1 (8.3%)	—	—
Participating in 24-hour cares was worthwhile	10 (83.3%)	2 (16.7%)	—	—	—	—
At discharge I felt adequately prepared to feed my child by bottle and/or feeding tube	11 (91.7%)	1 (8.3%)	—	—	—	—
At discharge I felt capable of correctly mixing my child's high calorie formula or breast milk	10 (83.3%)	2 (16.7%)	—	—	—	—
At discharge I felt capable of completing the daily home monitoring tasks of calculating weight gain/loss, adding volume totals and recording information in the log book	11 (91.7%)	1 (8.3%)	—	—	—	—
The pre-discharge conference call between me, the home monitoring team and my child's pediatrician was worthwhile	3 (27.3%)	3 (27.3%)	5 (45.5%)	—	—	1 (8.3%)
The program is more challenging to follow than I expected	—	2 (16.7%)	1 (8.3%)	5 (41.7%)	4 (33.3%)	—
Would you have found it helpful to speak to another parent who has participated in the home monitoring program?	2 (16.7%)	4 (33.3%)	5 (41.7%)	—	1 (8.3%)	—

## Results

100% Interstage survival rate for this cohort; similar to institution survival rate of 98% since 2000

### Patient Variables:

- Population Gender: 9 male, 3 female (n=12)
- Mean age at S1P: 7 days (range 3-14 days)
- Mean age at S1P discharge: 48 days (range 23-89 days)
- Mean age at time of S2P: 115 days (range 82-148 days)
- Mean duration of interstage period: 67 days (range 25-104 days)

### Face to Face Teaching Time:

- On average, teaching was initiated 21 days prior to discharge
  - Each family received approx. 3 teaching sessions, 50min. in length (range 15-100 min. each)
  - Mean total teaching time: 153 min. (range 90-340 min.)

### Interstage Calls:

- Mean frequency of interstage calls: 15 per patient (range 5-25)
- Six infants (50%) experienced a breach of criteria identified by a parent
- No parents failed to report a breach of criteria

### Interstage Clinic Visits:

- Mean number of clinic visits: 4 per patient (range 1-6)
- Four infants (33%) required unscheduled clinic visits due to breach in criteria or other physiologic concerns detected by parents

### Re-admissions:

- Seven infants (58%) required re-admission to hospital due to breach in criteria or other physiologic concerns
  - From scheduled clinic visits: n=3
  - From unscheduled clinic visits: n=1
  - From telephone call: n=4
- No infants presented with a serious adverse event

## Conclusions

- Participation in HMP positively impacts interstage survival
- Current face to face teaching time of approx. 150 min. appears adequate in preparing families for discharge into the HMP
- Current education strategies enable parents to carry out daily HMP tasks and correctly identify and report breach of criteria or other concerns
- Implementation of parent to parent mentoring program is perceived as beneficial by majority of HMP families
- The benefit of an interdisciplinary pre-discharge conference call in this cohort requires further investigation

## Limitations

- Small sample size
- Not blinded or randomized