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The 'surprise' question in paediatric palliative care: A prospective cohort study

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Abstract

Background: The question 'would you be surprised if this patient died in the next 12-months' is widely used for identifying adult patients in the last year of life. However, this has not yet been studied in children.

Aim: To assess the prognostic accuracy of the surprise question when used by a multidisciplinary team to predict survival outcomes of children with life-limiting conditions over a 3 and 12 month period.

Design: A prospective cohort study.

Setting/participants: Six multidisciplinary team members working in a children's hospice answered a 3 and 12 month surprise question about 327 children who were either newly referred or receiving care at the hospice between 2011 and 2013.

Results: The prognostic accuracy of the multidisciplinary team for the 3 (and 12)month surprise question were: sensitivity 83.3% (83.3%), specificity 93.2% (70.7%), positive predictive value 41.7% (23.6%), negative predictive value 99% (97.5%) and accuracy 92.6% (71.9%). Patients with a 'no' response had an increased risk of death at 3 (hazard ratio, 22.94, $p \leqslant 0.001$) and 12 months (hazard ratio, 6.53, $p \leqslant 0.001$).

Conclusion: The surprise question is a highly sensitive prognostic tool for identifying children receiving palliative care who are in the last 3 and 12 months of life. The tool is accurate at recognising children during stable periods demonstrated through a high negative predictive value. In practice, this tool could help identify children who would benefit from specialist end of life care, act as a marker to facilitate communications on advance care planning and assist in resource allocation.

Keywords

Paediatric, palliative care, prognosis, survival

What is already known about the topic?

- In adults, the surprise question has been recognised as a potential tool for identifying patients at risk of dying within the next 12-months.
- Early recognition of deterioration can result in timely access to specialist services that meet patient needs.
- The surprise question is used as part of the Gold Standards Framework in adult palliative care.

What this paper adds?

- The first to test the prognostic accuracy of the surprise question in a paediatric population.
- Analyses predictions made by a multidisciplinary team for children with a range of life-limiting conditions.
- The surprise question is found to be a highly accurate prognostic tool for children who are in the last 3 and 12 months of life.

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Implications for practice, theory or policy

- A 'no' response to the surprise question can be useful marker to introduce advance care planning discussions.
- May be incorporated into service planning to offer resources that align with patient end-of-life needs.

Introduction

The number of children with life-limiting or life-threatening conditions is increasing every year.[1,2] Medical advances have improved treatments for these children and evidence shows they are now living longer.[2] However, the reality is that many of these young people have highly complex needs and require considerable input from specialist services to meet their needs and maximise their quality of life.[3] The World Health Organization estimates that globally 1.2 million children are in need of palliative care at end of life.[4] Life expectancy is one of the most influential factors when assessing whether children should be referred to palliative care services.[5] However, referrals can occur in the late stages of illness[6] leaving less time to coordinate and implement appropriate care. Additionally, it can be equally challenging to identify which children under palliative care services are at risk of dying in the near future. These factors may, in part, be due to the lack of any reliable and clinically useful prognostic tool for this cohort of patients.

A patient's prognosis can be assessed using one of the many assessment measures that are available.[7] However, the surprise question 'would you be surprised if this patient died in the next twelve months?' may be a simple yet accurate way of identifying those who are at risk of dying. Studies assessing the value of the surprise question have produced mixed results. Some studies report good prognostic values with sensitivity ranging from 75% to 95% when predicting survival across weeks, months and a year.[8–10] These high sensitivity values are comparable to validated prognostic measures.[8,11,12] However, other studies have reported that 38%–80% of patients who die are not correctly identified when using the surprise question, nevertheless they do show good accuracy in recognising which patients will remain stable.[13–16] Patients who receive a 'yes' response to the surprise question (expected to survive) are found to live significantly longer than those who are given a 'no' response (expected to die).[8–10,13,14] Furthermore, the surprise question is significantly associated with patient survival outcomes with a 'no' response being linked to an increased risk of death.[9,10,13–16] The UK Gold Standards Framework Prognostic Indicator Guidance recommends that the surprise question can be used as a first step in recognising patients nearing end of life to facilitate better planning and proactive person-centred palliative care.[17] Versions of the surprise question are incorporated into paediatric measures such as the Spectrum of Children's Palliative Care Needs[18] and the Paediatric Palliative Screening Scale.[19] However, there are currently no studies to provide evidence that the surprise question is an accurate prognostic tool for identifying children who are nearing end of life. Therefore, there is uncertainty if the tool is relevant and accurate for use with this population.

If this tool is found to be an accurate prognostic indicator in paediatrics, its application will aid clinicians in recognising children in the last year of life and enable them to plan and facilitate specialist care. Furthermore, knowing that a child may be nearing end of life is important for preparing families and can prompt healthcare professionals to introduce advance care planning discussions. When death is not anticipated, it can result in limited opportunities for families to make appropriate preparations and informed decisions around a child's end of life.[20] The aim of this study is to assess the prognostic accuracy of the surprise question by measuring a multidisciplinary team's predictions of survival outcomes over 3 and 12 months in children who fit the umbrella for palliative care.[21]

Methods

Study design

This is a prospective study undertaken at Shooting Star Chase Children's Hospice (SSC) in England. This hospice cares for babies, children and young people and currently supports nearly 700 families.[22] Children under the care of this service have a diagnosis of a life-limiting or life-threatening condition and can be seen until they reach 21 years of age. As a result of their condition, these children are classified as having palliative care needs, although many are not at imminent risk of dying.

Participants

All children referred to SSC are discussed at a panel meeting to ensure they meet the hospices referral criteria before being accepted on to the service. Each case is reviewed annually to ensure the child still meets the criteria and can continue to receive support. This study used convenience sampling by enrolling all newly referred patients or those undergoing annual review at SSC between 2011 and 2013. All core staff members who regularly attended these meetings participated in this project.

Table 1. Patient demographics.

Variable	Total	%	Died within 3-months	Died within 12-months
Age (mean)	7.65 (SD = 5.34; range 0–20)			
Gender				
Girls	142	43.4	8	15
Boys	185	56.6	11	17
Primary diagnosis[a]				
Neurology	129	39.4	3	8
Congenital	79	24.2	3	8
Metabolic	39	11.9	0	2
Perinatal	31	9.5	2	2
Oncology	27	8.3	11	12
Haematology	5	1.5	0	0
Circulatory	3	0.9	0	0
Other	14	4.3	0	0
Total	327		19	32

[a]Primary diagnosis as per Fraser et al.[23]

Data collection

For each patient discussed during review panels, members of the multidisciplinary team (MDT) were asked to independently answer a 3-month surprise question (would you be surprised if this patient died in the next 3-months?) and a 12-month surprise question (would you be surprised if this patient died in the next 12-months?). No answers were shared between the team to eliminate any bias. The consensus of the team was calculated, for this, assignment to the 'yes' or 'no' category was determined by the majority vote of the MDT. If there was an even divide, these cases were excluded from the analysis as no consensus was reached. Each patient was followed up at 3 and 12 months to record their survival outcomes. Demographic and medical information was collected from patient case notes. This information included gender, age and primary diagnosis. The primary diagnoses of patients were coded using a system developed by Fraser et al.[23] based on the International Classification of Diseases, 10th edition (ICD-10).[24] The patient's diagnosis is categorised by the ICD-10 chapter heading that their condition falls into.

Due to the demands of working in the hospice environment, professionals were unable to attend every meeting to provide their responses for each child. Therefore, there is some variability in the number and type of professional who provided a response for each child. Missing responses were checked and found to be the result of non-attendance to meetings rather than not responding to the question. This study was approved by the Research and Clinical Governance Committee at SSC.

Statistical analysis

To measure the prognostic accuracy of the surprise question, the sensitivity, specificity, positive predictive value (PPV), negative predictive value (NPV) and overall accuracy were calculated for the consensus of the MDT. Sensitivity analyses were carried out to check the robustness of the results, given the choice to use the majority vote as the consensus of the team. Two sensitivity analyses were run, first with the consensus as 100% agreement among the MDT and second, with the consensus as 75%–100% agreement among the MDT. We attempted to explore the effects of age and diagnosis on prognostic accuracy. However, when patients were categorised by age (according to Royal College of Paediatrics and Child Health[25]), there were insufficient death events within each age category to find anything meaningful. Similar to age, there were a small number of deaths in many diagnostic categories. However, there were acceptable numbers to explore 12-month prognostic accuracy for the three diagnostic categories in which death was most prevalent: neurology, oncology and congenital.

Kaplan–Meier analyses were conducted to create survival curves over 3 and 12 months and the log-rank test was run to compare the number of days patients survived between those who receive a 'yes' and 'no' response to the surprise question. Univariate and multivariate Cox regression were used to analyse factors associated with an increased risk of death at 3 and 12 months. Patient age, gender and diagnosis (neurology, oncology, congenital and other) were included in the model in addition to surprise question response. Variables with a p value of <0.05 in the univariate model were included in the multivariate analysis.

Results

A total of 327 children (Table 1) with a range of life-limiting conditions were included in this study. There were a total of 142 girls and 185 boys in the study with a mean age of

Table 2. Cross tabulation of surprise question response and patient outcomes.

Category	Deceased	Living	*N*
Majority vote 3-months			
Not surprised	15	21	325[a]
Surprised	3	286	
Majority vote 12-months			
Not surprised	25	81	306[b]
Surprised	5	195	
100% agreement 3-months			
Not surprised	14	7	238
Surprised	1	216	
100% agreement 12-months			
Not surprised	21	36	175
Surprised	1	117	
75%–100% agreement 3-months			
Not surprised	14	12	290
Surprised	3	261	
75%–100% agreement 12-months			
Not surprised	24	56	236
Surprised	2	154	
Neurology 12-months			
Not surprised	7	21	122
Surprised	1	93	
Oncology 12-months			
Not surprised	12	10	27
Surprised	0	5	
Congenital 12-months			
Not surprised	4	20	73
Surprised	2	47	

[a]Two cases were excluded as no consensus was reached.
[b]Twenty-one cases were excluded as no consensus was reached.

7.65 years (standard deviation (SD) = 5.34, range = 0–20). Of the 327 participants within this study, 19 (5.8%) died within 3-months and 32 (9.8%) died within 12-months of the surprise question being asked. The MDT members who provided responses to the surprise question included a Consultant in Paediatric Palliative Medicine, General Practitioner, Head of Hospice Nursing Care, Specialist Symptom Care Nurse, Named Hospice Nurse and Administrator.

A cross tabulation of the surprise question responses and actual patient outcomes was performed for each analysis (Table 2). When calculating the MDT consensus, 2 cases were excluded for the 3-month surprise question and 21 cases were excluded for the 12-month surprise question as no agreement was achieved. Of the 23 cases that were excluded, three cases were patients who died within 12-months.

The prognostic accuracy of the MDT and sensitivity analyses and are shown in Table 3. At 3-months, the prognostic results were sensitivity 83.3%, specificity 93.2%, PPV 41.7% and NPV 99%. At 12-months, the prognostic results were sensitivity 83.3%, specificity 70.7%, PPV 23.6% and NPV 97.5%. Predictions made for children with a neurological condition were the most accurate overall (accuracy 82%); however, the MDT showed 100% sensitivity when predicting which children would die from cancer. Sensitivity analyses showed only a small amount of variability in prognostication results across 3 and 12 month predictions when restricting the consensus to 100% agreement and more than 75% agreement. Kaplan–Meier survival curves revealed a significant difference in days survived with those in the 'yes' category surviving for more days than those in the 'no' category for both 3 and 12 month predictions ($p < 0.001$; Figure 1). Univariate Cox regression (Tables 4 and 5) showed that at 3-months, age (hazard ratio (HR), 0.88, $p = 0.017$), diagnosis ($p < 0.001$) and response to the surprise question (HR 51.34, $p < 0.001$) were associated with an increased risk of dying. Similarly at 12-months, age (HR = 0.89, $p = 0.004$), diagnosis ($p < 0.001$) and response to the surprise question (HR = 10.90, $p < 0.001$) were associated with an increased risk of dying. Gender was not significant at either time point ($p > 0.05$). In multivariate Cox regression (Tables 4 and 5), response to the surprise question was the only predictor that remained significantly related to an increased risk of dying at both time points. Patients who received a 'no response' were 22.94 ($p < 0.001$) times more likely to die within 3-months and 6.53 ($p < 0.001$) times more likely to die within 12-months. Diagnosis was also significant in the 12-month multivariate model, with a diagnosis of oncology being associated with increased risk of death compared to the reference category (HR = 4.36, $p < 0.002$).

Discussion

To our knowledge, this is the first study to test the prognostic accuracy of the surprise question in a paediatric population and to include predictions from a variety of professionals within a MDT. The application of the surprise question in this study has produced some encouraging results. The high sensitivity at both time points indicates that the majority of children who were dying were correctly identified by the MDT using the surprise question. There was a very high NPV demonstrating that professionals are highly accurate in predicting children whose disease will remain stable over a 1-year period. There were few patient deaths that were not anticipated by the team. The specificity values were also high at 3-months although findings were lower for 12-months. A low PPV reflected the over categorisation by the MDT into the 'no' category at both time points. There were a proportion of patients who lived beyond the expectations of the team, and this occurred more frequently when making long-term predictions. This may be explained by the large number of children with non-progressive conditions within the hospice care population. These children

Table 3. Prognostic test results.

Category	Sensitivity	Specificity	PPV	NPV	Accuracy	*n*
3-month surprise question						
Majority vote	83.3% (60–95)	93.2% (89.7–95.5)	41.7% (27.1–57.8)	99% (96.9–99.8)	92.6% (89.2–95)	325
100% agreement	93.3% (68.2–99.9)	96.9% (93.5–98.6)	66.7% (45.2–83)	99.5% (97.2–99.9)	96.6% (93.4–98.4)	238
75%–100% agreement	82.4% (58.2–94.6)	95.6% (92.4–97.6)	53.9% (35.5–71.3)	98.9% (96.6–99.8)	94.8% (91.6–96.9)	290
12-month surprise question						
Majority vote	83.3% (66–93.1)	70.7% (65–75.7)	23.6% (16.5–32.6)	97.5% (94.1–99.1)	71.9% (66.6–76.6)	306
100% agreement	95.5% (76.5–99.9)	76.5% (69.1–82.5)	36.8% (25.5–49.9)	99.2% (94.9–99.9)	78.9% (72.2–84.3)	175
75%–100% agreement	92.3% (74.7–99)	73.3% (67–78.9)	30% (21–40.8)	98.7% (95.2–99.9)	75.4% (69.5–80.5)	236
Neurology	87.5% (50.8–99.9)	81.6% (73.4–87.7)	25% (12.4–43.6)	98.9% (93.6–99.9)	82% (74.1–87.9)	122
Oncology	100% (78.4–100)	33.3% (15–58.5)	54.6% (34.7–73.1)	100% (59.9–100)	63% (44.2–78.5)	27
Congenital	66.7% (29.6–90.8)	70.2% (58.3–79.8)	16.7% (6.1–36.5)	95.9% (85.5–99.7)	69.9% (58.5–79.2)	73

PPV: positive predictive value; NPV: negative predictive value.
95% confidence intervals are displayed in parentheses.

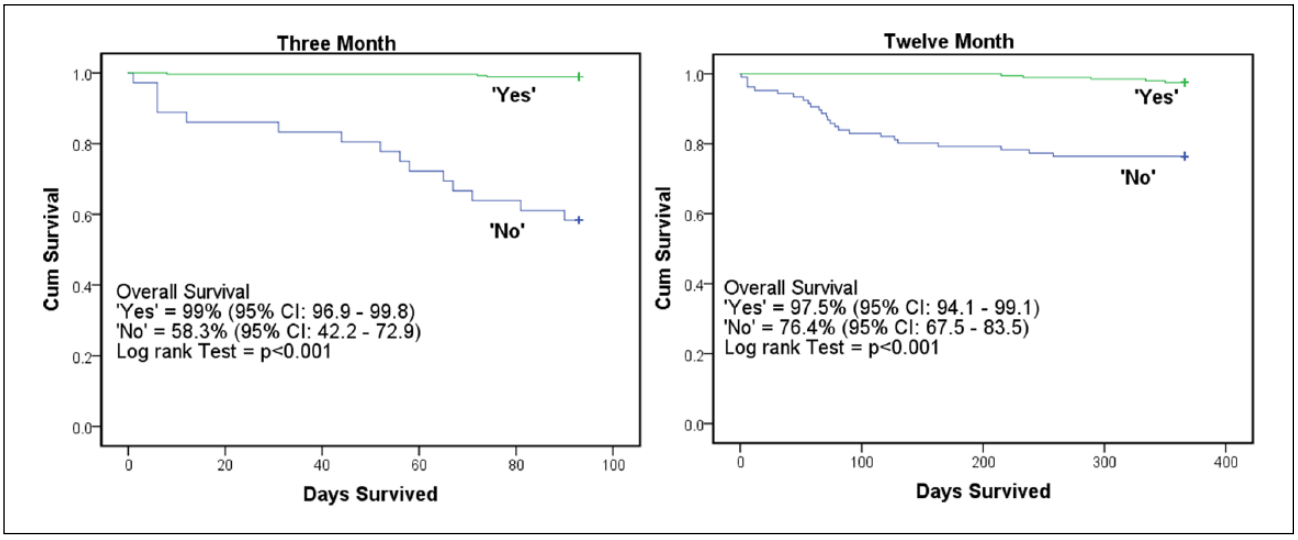

Figure 1. Kaplan–Meier survival curves.

are known to experience fluctuations in their health and with each episode of acute illness there is uncertainty if they will recover. Therefore, when making predictions for this population, professionals may anticipate a number of incidents of poor health over a 12-month period any of which could result in a child dying, hence the over reporting of some children into the 'no' category.

The sensitivity analyses demonstrated that the decision to use the majority vote of the MDT did produce a slightly lower overall accuracy; however, it did not have a large impact on the prognostication results when compared to a consensus that was restricted to either 100% or 75%–100% agreement among the MDT. Therefore, the majority vote could be considered the more conservative approach while allowing a larger sample size to be maintained.

Survival analyses demonstrated that the surprise question was highly associated with an increased risk of death.

Table 4. Univariate and multivariate Cox regression (3-months).

Variable	Univariate analysis			Multivariate analysis		
	Hazard ratio	CI	*p*	Hazard ratio	CI	*p*
SQ response	51.34	14.83–177.75	<0.001	22.94	5.34–98.60	<0.001
Diagnosis						
Neurology	RC			RC		
Oncology	21.1	5.88–75.75	<0.001	4.95	1.20–20.47	0.027
Congenital	1.65	0.33–8.16	0.541	1.26	0.25–6.26	0.779
Other	0.92	0.15–5.53	0.931	1.32	0.22–8.03	0.761
Overall			<0.001			0.087
Age	0.88	0.79–0.98	0.017	0.94	0.85–1.05	0.293
Gender	0.95	0.38–2.35	0.906			

CI: confidence interval; RC: reference category; SQ: surprise question.

Table 5. Univariate and multivariate Cox regression (12-months).

Variable	Univariate analysis			Multivariate analysis		
	Hazard ratio	CI	*p*	Hazard ratio	CI	*p*
SQ response	10.90	4.17–28.49	<0.001	6.53	2.32–18.40	<0.001
Diagnosis						
Neurology	RC			RC		
Oncology	9.89	4.03–24.26	<0.001	4.36	1.69–11.21	0.002
Congenital	1.66	0.62–4.40	0.311	0.94	0.32–2.72	0.905
Other	0.69	0.21–2.29	0.546	0.52	0.15–1.73	0.284
Overall			<0.001			<0.001
Age	0.89	0.82–0.97	0.004	0.94	0.87–1.01	0.088
Gender	1.15	0.58–2.30	0.692			

CI: confidence interval; RC: reference category; SQ: surprise question.

In the multivariate model, patients were significantly more likely to die within 3 and 12 months if they received a 'no' response to the surprise question. The surprise question response was more predictive of survival outcome than age or diagnosis at both time points.

Overall, the prognostic results found in this study are comparable and in some instances more accurate than those in adult populations,[8–10,15,16] suggesting that the surprise question may have the potential to become as widely used in children as it currently is for adults. Our finding that death was over predicted is also found in adult studies which use the surprise question. However, there is some conflicting data available from other prognostic studies which report that clinicians are optimistic about patient outcomes and over predict survival.[26,27] Prognostication is typically an assessment of a patient which aims to answer 'how long will the patient live'. By contrast, the surprise question is unique in the way it is worded and interpreted and professionals have expressed their preference in the 'implicit uncertainty' in the way the question is framed.[28] This subtle difference in language leads to a distinction between definitively 'expecting' death and the 'possibility' of death which may explain the conflicting findings between prognostic studies which use the surprise question and those that do not.

Implications for clinical practice

The findings from this study demonstrate that the surprise question is a clinically feasible tool that is accurate in identifying children under hospice care services who are at risk of dying within the next 3 and 12 months. The tool could prompt earlier recognition of shortened life expectancy in this population leading to end-of-life care planning and the allocation of the appropriate resources to meet their needs. This study has demonstrated that the surprise question is applicable to a range of paediatric life-limiting illnesses, reducing the need for disease-specific prognostic measures.

The small number of unexpected deaths (false negatives) found in this study is a positive finding and supports the surprise question as a good screening tool. The over prediction of death by the MDT (false positives) might not be considered a serious outcome in the context of the surprise question compared to other diagnostic tests. However, there are risks of causing distress to families in addition to

cost and resource implications for palliative care providers if death is anticipated but does not occur.

In terms of service provision, this study found that only a small proportion of hospice care children who are under the life-limiting umbrella[21] are at risk of imminent death. This indicates that there are many children who are receiving ongoing and/or respite care rather than specialist end-of-life care within this setting. Incorporating the surprise question into service planning could facilitate a tailored approach to care in which children receive the appropriate resources that align with their needs.

The ideal time to introduce discussions around end of life and advance care planning to families is difficult to ascertain. Raising this at diagnosis or during stable periods can be difficult as death is not in the immediate future, although making end-of-life decisions when a child is seriously unwell and end of life is imminent is equally challenging.[29] Therefore, a 'no' response to the surprise question may be a useful marker for clinicians to introduce advance care planning discussions to families. This process allows children and families to communicate their wishes, preferences and decisions and can lead to better planning and end-of-life care.[2,20]

Limitations

There are several limitations to this study. There were a relatively small number of deaths with only 9.8% of the sample dying within 12-months. Therefore, it was not possible to fully explore the effects of age and diagnosis on prognostic accuracy, and the MDT predictions were limited to a small number of children. Additionally, there were a high number of false positives found in this study. Thus, while the surprise question can be a useful tool to estimate which children are at risk of dying, other specific factors used in other tools such as clinical indicators, performance status and risk factors[26] should also be considered when a more precise prognosis is required. The heterogeneity of the sample may be considered a limitation of this study, although the sample is reflective of the broad spectrum of children under hospice care services. This is a single-centre study conducted in a hospice with a population of children who have been identified as unlikely to reach their 19th birthday; therefore, findings of this study are not generalisable beyond this context. It would be interesting for future researchers to explore the application of the surprise question in general paediatrics to see if it can be utilised to encourage earlier referral to palliative care services.

Conclusion

The surprise question has been demonstrated to be a sensitive measure in identifying children at risk of dying within 3 and 12 months, as well as identifying stable patients over the same time period. It is a useful screening tool that can be used for service planning when looking at tailoring and enhancing services for children in the last 3 and 12 months of life. This can result in timely access to services that align and meet the needs of children at end of life while facilitating advance care planning discussions.

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A-K.A. and A.M. contributed to concept and design. All authors contributed to data analysis and interpretation and drafting and revision of the article. All authors approved final version for publication.

Data management and sharing

Data can be obtained by contacting the authors of the paper by email to: kimberleyburke@nhs.net or lucycoombes@nhs.net

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

Ethical approval

This study was approved by the Research and Clinical Governance Committee at Shooting Star Chase Children's Hospice in January 2011.

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