



A pilot study comparing parent and adolescent online health information seeking behaviours in elective pediatric surgical situations

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Abstract

Purpose Little is known of how children seek health information. This study evaluates online health information (OHI) seeking behaviours in adolescents undergoing major elective surgical procedures and compares responses within parent–child dyads.

Methods With institutional approval, we prospectively surveyed parents of children admitted to our institution for major elective operations between November 2017 and November 2018, using convenience sampling. Patients aged 12 years and above were also invited. Each respondent completed an anonymized modification of a previously published survey on Internet usage. Chi squared tests were used for categorical data, with significance at P value < 0.05 .

Results Ninety-one parents and 19 patients (median age 15 years, range 12–18) responded, with 13 parent–child pairs. Daily Internet access was reported by 84 (93%) parents and 18 (95%) children, but OHI was sought in 77% of parents and 74% of children. Six (32%) children could not name their admitting condition, compared to 10 (11%) parents. Nine (50%) children consulted family and friends for information compared to 27 (30%) parents. Parents were more likely to access hospital websites ($n = 15$, 44%) compared to no children ($p = 0.01$), while most children ($n = 7$, 70%) accessed non-health websites (e.g. Wikipedia). In the 13 parent–child pairs, only one parent accurately assessed what their child understood of their condition. Most patients (63.6%) did not understand the aspects of their condition that their parents deemed important.

Conclusions This study highlights the differences in parental and child behaviours. Children are equally important to include when counselling. Surgeons can guide both parties to reliable Internet sources for health information.

Keywords Adolescent · Health information · Internet · Health literacy · Surgery

Introduction

In this digital age, the Internet is heavily used as a source of medical and health-related information [1–4]. This is particularly applicable to parents, who are playing an increasingly participatory role in their child’s healthcare and are seeking online health information (OHI) on their children’s conditions [5]. Their usage of OHI is not without reason: parents may feel less rushed when scouring the Internet for information compared to when asking a healthcare professional [6], and may consider online information to be more updated and convenient to access as compared to offline information [7].

However, there remains little literature describing the usage of OHI in caregivers of children with surgical conditions, and even less so on children themselves [5, 8, 9]. It is important to characterise such a phenomenon, given

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the potential for harm should parents or patients act upon incorrect information, or misinterpret information found on the Internet. Hence, this study aims to evaluate the OHI seeking behaviour in adolescents undergoing major elective surgical procedures. We also compare their responses to those of parents overall, and within parent–child dyads.

Materials and methods

Institutional approval was obtained for this study (CIRB No 2017/3013).

Study population

Using convenience sampling, we prospectively surveyed the following stakeholder groups:

1. Children aged 12 years and above, admitted to our institution for major elective operations between November 2017 and November 2018.
2. Parents of any child up to 18 years old, admitted to our institution for major elective operations between November 2017 and November 2018.

‘Major elective’ surgical procedures were any general surgical or orthopedic operations performed in children, as defined by administrative operative table codes determined by our institution.

We excluded the following:

1. Participants who were not fluent in English (as the questionnaire was written in English).
2. Parents who were aged under 18 years, or over 80 years.

We attempted to interview patients younger than 12 years old, but could not obtain complete response sets that were meaningful for analysis, thus the age cut-off.

Recruitment of participants

Interviewers approached participants with a fixed script to obtain informed consent. Participants were approached in the inpatient wards after the procedure had been performed, allowing for a suitable recovery period and when deemed clinically appropriate, but prior to the patient’s discharge. Interviewers consisted of one of 4 trained coordinators, who were not part of the clinical team managing the patients.

Survey design

The survey used in a previous study from our institution [9] was modified for our current study. Pilot surveys on both

parents ($n=5$) and children ($n=8$) were run to test for readability, with the survey further modified accordingly. The final versions of the survey had 20 questions for parents, and 19 questions for children. The survey for children was differed slightly from that for parents, to assess the child’s unique viewpoint and to account for age appropriate understanding of terms used. The survey comprised questions on:

- Demographic data.
- Knowledge of child’s condition.
- Internet usage.
 - Access to and frequency of usage of the Internet.
 - Usage of the Internet to access medical information.
 - Websites and keywords used when accessing medical information.
 - Perception of usefulness of online healthcare-related resources.
- Alternative sources of information regarding child’s condition.
- Child’s level of understanding of their own condition, as well as parental perceptions of the child’s understanding.

Google Forms was chosen as the platform to host our surveys. Based on interviewer and participant preferences, responses were either keyed into Google Forms in real time by the interviewer or participant, or recorded onto a hard-copy form to later be transferred onto Google Forms. The responses were anonymised. Besides the section for parental consent or child assent, no other personal data was collected.

Data analysis

We compared the child and parent responses overall. Where complete responses were available for parent–child pairs, we also compared intra-dyad responses. Chi-squared tests were used for categorical data, with $p < 0.05$ considered significant.

Results

We approached 109 parents, of whom 91 responded. Majority were mothers ($n=63$, 69%), with their children’s ages ranging from 0.6 to 18 years, median 5 years.

Of 25 children approached to participate, 19 agreed (median age 15 years, range 12–18). There were 13 parent–child pairs with complete responses.

Six (31.6%) children could not name their admitting condition, compared to 10 (11%) parents (Table 1).

Nine (50%) children consulted family and friends for information compared to 27 (29.7%) parents (Table 2).

Table 1 Comparison of knowledge of patient's condition

| | Parent, N=91 | Patient, N=19 | Total, N=110 |
|---|-----------------|------------------|-----------------|
| Do you know the name of your child's current condition/what your child's condition is about? (n, %) | | | |
| Yes | 81 (89.0) | 13 (68.4) | 94 (85.5) |
| No | 10 (11.0) | 6 (31.6) | 16 (14.5) |

Table 2 Comparison of sources of information on patient's condition between parents and children

| | Parent, N=91 | Patient, N=18 | Total, N=109 |
|---|-----------------|------------------|-----------------|
| What information resources, other than the Internet, did you use to learn about your child's current condition? ^a (n, %) | | | |
| GP/family doctor | 58 (63.7) | 11 (61.1) | 69 (63.3) |
| Other health workers that are not doctors e.g. nurses | 11 (12.1) | 1 (5.6) | 12 (11.0) |
| TV/radio | 3 (3.3) | 0 (0.0) | 3 (2.8) |
| Friends and families | 27 (29.7) | 9 (50.0) | 36 (33.0) |
| Books/printed materials | 11 (12.1) | 3 (16.7) | 14 (12.8) |
| None | 17 (18.7) | 5 (27.8) | 22 (20.2) |

GP general practitioner

^aMore than one answer allowed

Table 3 Comparison of Internet access and online health information seeking behaviour between parents and children

| | Parent, N=91 | Patient, N=19 | Total, N=110 |
|--|-----------------|------------------|-----------------|
| Do you have Internet access at home? (n, %) | | | |
| Yes | 91 (100.0) | 18 (94.7) | 109 (99.1) |
| No | 0 (0.0) | 1 (5.3) | 1 (0.9) |
| How often do you use the Internet? (n, %) | | | |
| Daily | 84 (92.3) | 17 (89.5) | 101 (91.8) |
| More than 3 times per week | 3 (3.3) | 1 (5.3) | 4 (3.6) |
| Less than 3 times per week | 3 (3.3) | 0 (0.0) | 3 (2.7) |
| More than 3 times per month | 0 (0.0) | 0 (0.0) | 0 (0.0) |
| Less than 3 times per month | 1 (1.1) | 1 (5.3) | 2 (1.8) |
| Did you search the Internet to learn about the patient's current condition? (n, %) | | | |
| Yes | 70 (76.9) | 14 (73.7) | 84 (76.4) |
| No | 21 (23.1) | 5 (26.3) | 26 (23.6) |

Daily Internet access was reported by 84 (92.3%) parents and 17 (89.5%) children but OHI was sought in 76.9% of parents and 73.7% of children (Table 3).

Parents were more likely to access hospital websites ($n = 15$, 44.1%) compared to no children ($p = 0.01$), while most children ($n = 7$, 70%) accessed non-health websites (e.g. Wikipedia) (Table 4).

Most parents (95.7%) and all children (100%) found the information on the Internet useful. Notably, where parents did not find the Internet useful, the most common reasons included too much information (22.1%) and information that was too technical, while for children, the most common reason was too little information (36.4%) (Table 5).

While most parents (91.4%) and patients (92.3%) agreed that the information found online was the same as that given by the doctor, most patients (92.9%) did not discuss the information found online with their doctor, compared to 50% of parents (Table 6). Reasons for not discussing the online information with their doctor was similar between both groups, with the information having already been covered by the doctor being the most common reason given.

In the 13 parent–child pairs, only one parent accurately assessed what their child understood of their condition. Most patients (63.6%) did not understand the aspects of their condition that their parents deemed important.

Of the parents who had children aged 12 and above, majority (69.6%) had taken steps to educate their child on their condition (Table 7). Majority (81.3%) used the Internet, as well as their family doctor (62.5%) in educating their child.

Discussion

The internet is a valuable resource for both caregivers and patients. Our study shows that a high proportion of parents access the Internet for help on their child's medical condition. In addition, children themselves also do so, but with crucial differences in search patterns compared to parents.

As the lines between digital and physical worlds increasingly blur, looking for online health information has become a natural extension in the healthcare journey of both parent and patient. The benefits are many, including round-the-clock access, provision of privacy particularly when seeking information on personally sensitive issues such as sex or gender health, and the ability to connect with other peers experiencing similar health issues [10]. Meanwhile, it is only recently that the medical profession has harnessed digital technology in providing reliable and accurate health information to both patients and professionals, often playing catch-up rather than leading the way [11].

In our study, home internet availability (98.3%) and internet usage (90.3% reporting daily usage) were high and similar to other studies conducted in developed countries [5, 8, 12]. Search patterns were similar across groups, with many using reputable websites, and nearly all caregivers and children finding the information useful. The majority of parents in our study (75.4%) used the Internet to learn about their child's admitting condition. This is consistent with the findings in other studies, which report a steady

Table 4 Comparison of online sources of information on patient's condition between parents and children

| | Parent, N=34 | Patient, N=10 | Total, N=44 |
|---|-----------------|------------------|----------------|
| What are the top 3 websites you used to learn about your child's condition? ^a (n, %) | | | |
| Hospital/university based websites (e.g. MayoClinic) | 15 (44.1) | 0 (0.0) | 15 (34.1) |
| Medical journal/reference websites (e.g. Medscape, PubMed, eMedicine) | 6 (17.6) | 1 (10.0) | 7 (15.9) |
| Government websites (e.g. MedlinePlus) | 2 (5.9) | 2 (20.0) | 4 (9.1) |
| Child health specific websites run by healthcare professionals | 3 (8.8) | 0 (0.0) | 3 (6.8) |
| Other health websites (e.g. WebMD, Healthline, MedicineNet, Physioworks) | 17 (50.0) | 7 (70.0) | 24 (54.5) |
| Popular parenting websites | 1 (2.9) | 0 (0.0) | 1 (2.3) |
| Others | 14 (41.2) | 7 (70.0) | 21 (47.7) |

^aMore than one answer allowed

Table 5 Opinion on the usefulness of the online information

| | Parent, N=70 | Patient, N=14 | Total, N=84 |
|--|-----------------|------------------|----------------|
| Did you find the information on the Internet useful? (n, %) | | | |
| Yes | 67 (95.7) | 14 (100.0) | 81 (96.4) |
| No | 3 (4.3) | 0 (0.0) | 3 (3.6) |
| | Parent, N=67 | Patient, N=14 | Total, N=81 |
| How was the information useful? ^a (n, %) | | | |
| Further understanding of my/my child's current condition | 63 (94.0) | 13 (92.9) | 76 (93.8) |
| Reassurance and support | 39 (58.2) | 5 (35.7) | 44 (54.3) |
| Others | 0 (0.0) | 0 (0.0) | 0 (0.0) |
| | Parent, N=68 | Patient, N=11 | Total, N=79 |
| What wasn't useful? ^a (n, %) | | | |
| Too much information: I can understand the information, but there is a lot to read | 15 (22.1) | 1 (7.1) | 16 (20.3) |
| Too little information | 6 (8.8) | 4 (36.4) | 10 (12.7) |
| Could not find any information | 0 (0.0) | 2 (18.2) | 2 (2.5) |
| Too technical: I cannot understand the information | 17 (25.0) | 3 (27.3) | 20 (25.3) |
| Distressing | 11 (16.2) | 3 (27.3) | 14 (17.7) |
| None | 8 (11.8) | 2 (18.2) | 10 (12.7) |
| Other | 2 (2.9) | 1 (7.1) | 3 (3.8) |

^aMore than one answer allowed

increase in parental usage of online information regarding pediatric conditions [8, 12–14]. This high reliance on the Internet for health information should be of concern to surgeons, given that multiple papers have reported the quality of OHI to be poor, and that users may not be sufficiently able to discern the credibility of the OHI [12, 15–18]. However, it was heartening also to see that over half of both parents and patients sought further information from doctors and non-physician health workers, implying trust in the expertise and knowledge of professionals, although this is admittedly

unusual in adolescent patients compared to other reports in the literature [19, 20].

There were significant differences seen between parents and patients in both online resources and in alternative offline sources of information. In our study, the types of websites used were different where parents were much more likely to access sites run by health professionals, compared to the patients who overwhelmingly used non-health websites such as Wikipedia [21]. Just as concerning is that 50% of parents and most children (92.9%) did not discuss this information with their doctor. This highlights an important

Table 6 Comparison of Internet sourced information to information from doctor

| | Parent, N= 70 | Patient, N= 13 | Total, N= 83 |
|---|------------------|-------------------|-----------------|
| Was the information found on the Internet the same as the information given by the doctor? (n, %) | | | |
| Yes | 64 (91.4) | 12 (92.3) | 76 (91.6) |
| No | 6 (8.6) | 1 (7.7) | 7 (8.4) |
| | Parent, N= 70 | Patient, N= 14 | Total, N= 84 |
| Did you discuss the information found on the Internet with your doctor? (n, %) | | | |
| Yes | 35 (50.0) | 1 (7.1) | 36 (42.9) |
| No | 35 (50.0) | 13 (92.9) | 48 (57.1) |
| | Parent, N= 35 | Patient, N= 12 | Total, N= 47 |
| If you did not discuss it with your doctor, why? ^a (n, %) | | | |
| Already covered by doctor | 27 (77.1) | 8 (66.7) | 35 (74.5) |
| Already asked by child/Parent or caregiver | 1 (2.9) | 2 (16.7) | 3 (6.4) |
| Information found not relevant | 2 (5.7) | 2 (16.7) | 4 (8.5) |
| Forgot to ask | 1 (2.9) | 3 (25.0) | 4 (8.5) |
| Not enough time to ask | 2 (5.7) | 0 (0.0) | 2 (4.3) |
| I did not feel comfortable discussing it with my doctor | 0 (0.0) | 1 (8.3) | 1 (2.1) |
| I do not wish to answer this question | 2 (5.7) | 1 (8.3) | 3 (6.4) |
| Others | 2 (5.7) | 0 (0.0) | 2 (4.3) |

^aMore than one answer allowed

Table 7 Methods via which parents educate their children on their condition

| | Parent, N= 23 |
|--|------------------|
| Have you taken steps to try to increase your child’s understanding of their current condition and of matters related to their current condition e.g. available surgeries, medications etc.? (n, %) | |
| Yes | 16 (69.6) |
| No | 7 (30.4) |
| | Parent, N= 16 |
| If yes, what resources have you used in educating your child? (n, %) | |
| Internet | 13 (81.3) |
| GP/family doctor | 10 (62.5) |
| Other health workers that are not doctors e.g. nurses | 3 (18.8) |
| TV/radio | 0 (0.0) |
| Friends and families | 4 (25.0) |
| Books/printed materials | 1 (6.3) |
| Other | 1 (6.3) |

GP General practitioner

gap in the reliability of information obtained by patients and should be targeted in initiatives to improve health literacy in adolescent patients and their parents [22]. Furthermore, given that majority (81.3%) of parents used the Internet to educate their child on their own condition, it is especially

important that both parents and children consume credible, accurate OHI.

In terms of offline sources, the patients we surveyed were more likely to seek information from their friends and families, which reflects their higher reliance on peer

educators, a known phenomenon in adolescents [23]. Peers, especially those facing similar health issues, are seen to provide emotional support and offer quick ‘fixes’, yet online patient communities and networks remain under-recognised and under-utilised by clinicians [24]. The use of mainstream media and publication materials was universally dismal.

Interestingly, where parents did not find the Internet useful, one of the most common reasons included too much information (22.1%), while for children, the most common reason was too little information (36.4%). This may be a reflection of the different Internet sources consulted by parents and children, or the differing expectations in how much information is needed for one to understand the child’s admitting condition: it is possible that children want more information than their parents, hence perceiving the same amount of online information as ‘too little’ while parents would perceive it as ‘too much’.

Our study has strengths in recruiting prospectively. Due to the widespread use of English in our society, language was not an obstacle. Interviewers were not part of the clinical teams managing the patients, minimising both interviewer and respondent bias. However, the patient cohort was small, with an even lower number of complete parent–child dyads, limiting what we can infer from their responses. We did not apply age cut-offs for the children of parents who responded, and it is possible that patient age might impact parental responses to the survey. Lastly, given the multiple-choice nature of the survey, the specific options included may also have influenced the parents’ responses, leading to recall bias. A semi-structured qualitative design might reveal nuances not apparent in our study.

Conclusion

The trend in parents and patients seeking online health information is likely to continue, with the Internet being viewed as essential to the healthcare journey. As such, it would be wise for doctors to view the Internet as an ally in patient education, and a powerful tool in enhancing patient care. Furthermore, children are equally important to include when counselling. Surgeons can guide both parties to reliable Internet sources for health information.

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