Adolescent and Caregiver Attitudes Towards Telemedicine Use in Pediatric Nephrology

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Abstract

Background: Telemedicine is increasingly utilized as an alternative to in person consultation. Current pandemic conditions are providing additional impetus to virtual care delivery. We aimed at comparing both pediatric patient and caregiver attitudes towards telemedicine (here as tertiary center to remote health care location) as a crucial determinant of longer-term effectiveness.

Methods: This mixed methods cohort study combined patient characteristics and analysis of transcribed structured telephone interviews with both pediatric nephrology patients (11-18 years) and their caregivers.

Results: For 11 child-parent dyads, the median distances to tertiary center were 191 km (range 110-1378 km) and 1 km (1-54 km) to remote telemedicine location. Overall a ratio of 2:1 for telemedicine to in-person visits was favored; with caregivers more in favor of remote care than patients. Qualitative analysis found that experiences with telemedicine were distinguished by *consultation-specific factors* and *contextual factors*. *Contextual factors* (travel/cost savings) were valued for telemedicine by patients and caregivers. *Consultation-specific factors*, such as the ability to show the doctor physical symptoms, were more valued during in-person consultations, especially by patients. The overall visit type preference was related to the nature of the consultation. For regular check-ups, and for patients with less complex needs, participants felt that telemedicine offered a comparable experience to in-person visits.

Conclusions: Indiscriminate transfer to chronic care predicated on mainly telemedicine approach is not compatible with user expressed attitudes (especially patients). Accurately mapping models of care to these attitudes is an essential determinant of effective management and longer-term engagement with potentially life-long health challenges.

Key Points

What is known about this subject? Information around attitudes towards telemedicine is currently limited, and exclusively focused upon the caregiver. There are no systematic evaluations of the pediatric patient perspective available at all.

What this study adds: Patients' attitudes differ from that of their caregivers. In general, adolescents valued in-person visits. Diagnosis and distance are major mediating factors for preference. Technical issues were listed as the major disadvantages. This study supports a blended approach to ongoing care, rather than exclusively relying on remote interaction.

Background

Telemedicine is increasingly used to provide clinical services to remote patients outside of tertiary care centers.[1] Telemedicine is advantageous in helping the provision of care to patients with the lack of mobility, decreased funding, and lack of staff situations faced by families in rural settings.[2] Specifically, significant challenges exist for pediatric patients living in remote locations who require attention from

specialized physicians,[3] given that outcomes are partially determined by distance from specialized centers.[4] Current pandemic conditions are further fueling adoption of virtual care delivery. Effective care is crucial to producing best care for patients but also to ensure that they remain engaged with health care and not lost in the transition to lifelong adult services.

Care in Ontario is widely dispersed. Ontario is twice the size of California but with only approximately one-third of the population; served by only 4 pediatric nephrology centers. Remote patients may live more than 1,400 km away from the tertiary center provided at The University of Western Ontario, London Health Science Centre. Telemedicine offers a means to provide timely care to patients in remote areas.[5, 6] Over a five year period 652,337 Ontario telemedicine network (OTN) visits were recorded.[6] Recently, there has been a surge of virtual care due to the COVID-19 pandemic.[7] Information around attitudes towards telemedicine is limited, and exclusively focused upon the caregiver.[8] There are no systematic evaluations of the pediatric patient perspective available at all.

With this mixed methodology study, we aimed to explore the attitudes of adolescent chronic pediatric nephrology patients and their caregivers towards telemedicine visits in comparison to in-person visits to our tertiary center. We also interrogated participants to establish their position on how in-person visits should take place (in relationship to telemedicine visits) and studied the relationships of these preferences to relevant demographic and geographic factors.

Methods

Brief Description of Virtual Encounters using the Ontario Telemedicine Network

The Ontario Telemedicine Network is one of the largest telemedicine networks in the world. It uses secure, encrypted two-way videoconferencing to provide access to care for patients in every hospital and hundreds of other health care locations across the province, where there typically is a nurse or a coordinator at the remote site. Physicians often use their desktop computers. During the COVID-19 pandemic, the network services were expanded to include handheld devices, laptops and other devices directly in the home of the patients. For the purpose of this study, we are focusing only on delivery of care in remote locations.

Study Design, Study Period, Population and Researchers

This was a mixed methods study using demographic data, patient characteristics and structured telephone interviews with 15 standardized questions to pediatric nephrology patients aged 11–18 years of age and their caregiver. The study was approved local Research Ethics Board (file number 108400). Written informed signed consent/assent was obtained for all subjects from caregivers and written informed assent was obtained from consenting minors. Patients and caregivers were approached in writing and enrolled between December 2017 and December 2019. Main inclusion criteria were having at least one telemedicine encounter and one caregiver. Twenty-four invitation letters were sent out in concert

with usual reminder for clinic attendance. Eleven patient dyads were recruited. We used purposeful sampling [8] to recruit patients representative of our wide geographical catchment area. This qualitative sampling strategy allowed us to explore similarities and differences in visit preferences based on geographic location. The interview questions were developed for this study and are provided in appendix 1. Interviews were conducted by YQ and BW, both were female undergraduate health sciences students at the time of the study. Both had undergone extensive research training and completed good clinical practice and standard operating procedure training at Lawson Research Institute. No previous relationship with the patients and caregiver was established. Their occupation and their desire to conduct research was disclosed in the letter of information. The interviews were conducted from the hospital.

Quantitative Methods

Patient demographics, visit number, diagnosis, distance to tertiary center, distance to telemedicine center, frequency of visits and patient address were obtained from the electronic medical record. We used simple descriptive statistics to analyze the data as appropriate. Continuous variables were analyzed for normal distribution using the D'Agostino-Pearson normality test.[9] Data were compared based on the distribution with either the t-test or the Mann-Whitney test. Categorical data were analyzed using Fisher's exact test or the chi-square test, as appropriate. Data were analyzed using GraphPad Prism version 5.0f for Mac, GraphPad Software, San Diego, CA, USA.

Qualitative Methods

Structured telephone interviews were conducted, audio recorded and then transcribed using NoNotes (v.19.11.0) for iPhone and analyzed using NVivo 12 Mac (QSR International Pty Ltd, Melbourne, Australia). We held individual/confidential interviews over the phone with patients and caregivers; to minimize bias from the other participant's opinions and views. Interviews were on average 15 minutes. We examined the dyads to look for similarities and differences between the family members. Using comparative analysis, we explored whether differences existed between participants travelling greater than 500 km compared with those travelling shorter distances.

The strategies of immersion and crystallization were used in order to identify key themes.[10] We used content analysis with an inductive process of comparative coding.[11] Open coding followed by axial coding allowed us to discover common categories of factors relating to preference of type of visit. Two researchers (YQ and SC) independently analyzed each interview, then met to discuss the emerging themes and categories. Where differences in coding arose, we reached consensus through a discussion of our interpretations.[12] The recruitment of new participants was terminated as the identified themes reached saturation. While the study was planned for 40 dyads, we reached saturation after 11 dyads. Transcripts were not returned to participants.

Results

Patient Demographics

We enrolled 11 patient/caregiver dyads. Five patients were male. The mean age of the patients was 14.4 ± 2.5 years (range 11.2–18.0). The median distance to tertiary center was 191 km (range 110–1378 km). The median distance saved was 190 km (range 88-1377 km) one way. Four patients lived more than 500 km from the tertiary center. The 11 patients had a total of 334 in person visits (mean 30 ± 25) and 86 telemedicine visits (mean 8 ± 7). The maximum of in person visits was 85 and the maximum of telemedicine visits was 21. There were 7 patient who had congenital conditions affecting them throughout life. One patient had received a kidney transplant, two had congenital genetic conditions, two had congenital anomalies of the kidneys and urinary tract, two had advanced chronic kidney disease, one each had renovascular hypertension, diabetic nephropathy and nephrotic syndrome, respectively. Patient demographic and geographical data are provided in Table 1.

Table 1
Patient demographics and geographical information.

	Minimum	25% Percentile	Median	75% Percentile	Maximum	Mean	Std. Deviation
Patient Age [years]	11.2	-	-	-	18	14.42	2.545
# OTN Visits	1	-	-	-	21	7.8	6.8
# In person Visits	2	-	-	-	85	30.4	25.3
Distance London OTN [km]	110	172.3	191	542.8	1378	-	-
Distance Home London [km]	100	154.8	191	553.3	1378	-	-
Distance Home OTN [km]	1	1	1	11.5	54	-	-
Distance saved [km]	88	144	190	535.8	1377	-	-
Perceived Time to London (Caregiver) [min]	60	86.25	120	195	720	-	-
Perceived Time to London (Patient) [min]	60	87.5	120	120	330	-	-
Perceived Time to OTN (Caregiver)	5	-	-	-	37.5	14.8	11.0
Perceived Time to OTN (Patient) [min]	5	-	-	-	30	15.8	9.6
Preferred Ratio (Caregiver)	1	-	-	-	5	2.9	1.5

OTN = Ontario Telemedicine Network, km = kilometer, min = minutes

	Minimum	25% Percentile	Median	75% Percentile	Maximum	Mean	Std. Deviation
Preferred Ratio (Patient)	0	-	-	-	3	1.5	1.1
OTN = Ontario Telemedicine Network, km = kilometer, min = minutes							

Some questions provided suitable data for quantitative analysis. We asked for preference for the visits and the preferred ratio. Five out of 11 patients (45%) preferred OTN and 6/11 patients (55%) preferred London in-person visits. Of the patients preferring OTN, 2/4 live more than 500 km away from the tertiary center, whereas the patients favoring the tertiary care center 4/7 patients live closer than 500 km away. This suggests that patients slightly preferred in-person visits regardless of distance to tertiary care centers. By contrast, only two caregivers preferred in-person visits whereas 3 preferred OTN, and the majority of 6 preferred a mixture. There was a significant difference between the patient and caregiver preferences ($p = 0.0239$, chi-square test).

The preferred ratio for care between OTN to in-person was a median of 3:1 (range 0–5) whereas the caregivers suggested a median of 1:1 (range 0–10, $p = 0.1311$, Mann Whitney test). When comparing distance and severity of the underlying diagnosis, there was neither a significant difference between a distance over and under 500 km nor between severe and less severe diagnosis. The combined preferred ratio of all participants was 2:1. The results are summarized in Table 2.

Table 2
Patient and caregiver responses to preferred ratio and preference

Dyad #	Preferred ratio (patient)	Preferred ratio (caregiver)	Preference (patient)	Preference (caregiver)
1	2:1	1:1	OTN	OTN
2	3:2	3:1	In-person	-
3	2:1	1:1	OTN	OTN
4	-	-	In-person	50/50
5	0:1	0:1	In-person	London in-person
6	3:1	1:1	OTN	Depends on appointment
7	-	1:1	In-person	Depends on season
8	4:1	1:1	OTN	Depends on season
9	3:1	3:1	OTN	50/50
10	3:2	2:1	In-person	London in-person
11	5:1	10:1	In-person	OTN

OTN = Ontario Telemedicine Network,

Qualitative Analysis

We identified a series of main themes reflecting the factors influencing preferences of patients and their caregivers. Each of these themes is described in more detail below and summarized in Table 3. Illustrative quotes are presented as exemplars of participant responses.

Factors associated with preferences emerged into two categories: consult-specific factors and context-specific factors relating to participants preferences. Consult-specific factors were identified as those that occur within the clinical encounter itself. Context-specific factors, on the other hand, were factors that occurred outside of the medical visit itself. These factors were further categorized as advantages and disadvantages to telemedicine and in-person visits. In addition to these factors, we identified factors mitigating preference for one type of consultation over the other. Overall, we found that consult-specific advantages came out as the primary reasons for participants' preference for in-person visits, while context-specific advantages were reasons for preferring telemedicine visits.

Consult-specific factors

In-person visits

During the interviews, participants identified consult-specific factors associated with preference for in-person consultations and telemedicine visits, categorized as advantages and disadvantages associated with both types of medical visit. Three consult-specific factors influencing preference for in-person consultations were expressed: comfort factors, ease of describing symptoms, and encounters being more personal.

Comfort factors included in-person visits provided patients and caregivers more psychological relief seeing the physician in-person. Further, participants expressed that they took more comfort in communicating with the physician in-person. As one patient commented, “in-person visits are so much more normal and more comfortable” than telemedicine.

Participants also appreciated the ease of describing symptoms in-person and the ability to show the physician physical signs during their appointment. As one patient noted, “when you have physical symptoms and stuff like that is easier for doctors to kind of tell what is causing them instead over a camera.” During the interviews, participants discussed the comfort factor of encounters are more personal. “to see him in-person is a lot easier to talk to him in person.” This level of comfort seems to at least partially balance out the main stated disadvantage of long wait times. A patient explained that with in-person visits, “it takes a long time to wait and to see my doctor”.

Telemedicine visits

During the interviews, participants expressed several consult-specific advantages that telemedicine visits had over in-person consultations. Participants appreciated the ability to stay close to home. One patient explained, “it’s usually better when I’m at home.”.

Participants provided two related, but differing perspectives on why telemedicine was favored over in-person consultations. While Some participants felt that there existed virtually no differences between a telemedicine visit and a phone or video chat. Many participants stated that they felt that telemedicine was the same as a telephone call. “during the visit it’s basically the same” one patient said. There were some participants who felt that during routine consultations, telemedicine offered the same advantages as in-person visits. “It’s like you’re able to get the same information across. Like it’s almost as if it is really face-to-face, but it’s just through a screen.”

Although some participants compared telemedicine to telephone calls some participants felt that telemedicine offered more than just a phone call. These participants felt that the face-to-face video interaction provided a more inclusive experience with the physicians. A caregiver explained that telemedicine was “a way to continue the relationship and the connection with the doctor.” Another patient explains the difference they see between telemedicine and in-person visits like this: “Compare it to like when I visit face-time my grandparents that live in Florida. They kind of see me but they don’t know how tall I am. It’s kind of different that way.” This quote acknowledges both the advantages and disadvantages of telemedicine visits.

The use of the conventional format of telemedicine (as used in the OTN model) presents some challenges. Even though telemedicine created convenience, the pre-set duration of the telemedicine visit led to some patients and caregivers feeling that telemedicine visits are somewhat rushed and there may not be enough time to adequately discuss all issues.

One stated consult-specific disadvantage to telemedicine visits expressed by participants was the potential for patients to take telemedicine visits less seriously, as the physician was not physically present. This was a concern primarily expressed by caregivers, although not exclusively. One caregiver explained that when “the doctor is in your face, keeps the child more accountable too because they’re right there.”

Context specific factors

In-person visits

There were few context-specific factors that participants stated as an advantage to in-person visits, other than participants saw an in-person visit as an opportunity to take a trip. As one patient said, “I like travelling to London because like we don’t travel often, so I like to go there sometimes”.

This was a greater advantage for participants coming from further than 500 kilometers away, although this advantage was often overshadowed by the disadvantages associated with the travel for in-person appointments, such as missing school, work and potential weather disruption.

Although in-person appointments were preferred for consult-specific reasons, caregivers, and to a lesser extent, patients, felt that travelling for appointments was a hassle. In-person visits were considered costly and travelling an unproductive use of time.

Telemedicine visits

Participants expressed a number of advantages to telemedicine appointment. Almost all caregivers and patients felt that telemedicine was more convenient and efficient use of time and money. Almost all participants expressed dissatisfaction with the technical elements of telemedicine, such as lag during the consultation and disconnections during the visit. As a caregiver explains, “it’s a bit odd, because there is that little bit of a delay when you’re talking to them from when they say something to when we actually kind of hear it. You see that little bit of a pause going.” For some participants, these pauses made it easier to forget things, such as instructions from the doctor. This delay in communication as a disadvantage of telemedicine was expressed by almost all the participants. All participants including both patients and caregivers felt that telemedicine was a safe way to communicate with their physician.

Factors mitigating preference

Factors mitigating the preference for type of visits were identified throughout the interviews. For routine and follow-up visits, participants preferred the telemedicine visits due to context-specific factors.

Potentially inclement Canadian weather was one key factor in determining preference. One participant explains that telemedicine is “good for like a regular check-up.” Travelling for in-person appointments was seen by some patients as a nice trip during the summertime. However, in-person visits required patients and caregivers to miss time from work or school to travel for the appointment. When the weather was better, participants were more likely to favor in-person appointments over telemedicine visits.

Health condition of the patient and the reason for the visit also influenced expressed preference. If the appointment was a regularly scheduled routine appointment, telemedicine visits were preferred. However, if there was a change in-patient condition or a specific concern to be addressed, in-person visits were preferred. When more extensive testing was required, the participants stated that they preferred to go to the hospital for an in-person visit. This was the most expressed factor mitigated preference for either type of visit.

Table 3
Themes, subthemes, and representative quotes from interviews

Themes	Subthemes		Quotes
Consult specific factors	In person advantages	**Comfort factors** - In person visits provide more relief - Personal comfort	They just give us a little bit more relief because it's one on one
		Ease of describing symptoms	Especially for me when you have physical symptoms and stuff like that is easier for doctors to kind of tell what is causing them instead over a camera
		Encounters are more personal	She's better one on one when she can actually see and touch the person as opposed to on the computer
	In person disadvantages	**Long wait times for appointments**	When you're at a … pediatric clinic … you sometimes can be waiting for quite some time
	Telemedicine advantages	**Staying close to home**	If I can have the answers on the comfort of my home and everything is working out so far for me, why not taking advantage of that
		Telemedicine calls are just like talking in person	It's like you're able to get the same information across. Like it's almost as if it is really face to face, but it's just through screen
		Telemedicine is more than a phone call	it's not just like a phone call so if he feels like something's off with her or she's not looking like herself he can even see that as well without actually having to be there
	Telemedicine disadvantages		

Themes	Subthemes		Quotes
		Technical hassles - Awkward talking through the computer - Harder for clear communication - Some delay or disconnect in calls - Technical issues with telemedicine	It's a bit odd, because there is that little bit of a delay when you're talking to them from when they say something to when we actually kind of hear it
		Telemedicine is a little rushed	Sometimes it doesn't last long and sometimes I have questions afterwards I should have ask him, but I couldn't
Context-specific factors	In person advantages	**Likes a trip**	I like travelling to London because like we don't travel often, so I like to go there sometimes
	In person disadvantages	**Travelling is a Hassle** - In person visits are costly - Travelling wastes time	I cannot fly straight to London. I have to go to London and then go to Toronto and from Toronto to London.
	Telemedicine advantages	**Option relieves stress**	There's relief for me as a mom, because we do not have a specialist here in town, to have that contact
		No dislikes about telemedicine	I like, honestly, I like everything about it. I have nothing that I really dislike about it.
		Telemedicine creates convenience - Easy to travel to telemedicine station - Telemedicine is on time - Telemedicine saves time	Well, it's usually after school, so I would just go right after school and it would only take max about an hour and it would be quick and it won't really disrupt my day.

Themes	Subthemes		Quotes
		Telemedicine is cost-efficient	You don't have to go through the process of booking a ticket or spending the money to get the ticket
		Telemedicine is safe	To me, it's way more comfortable to be here and it's safe because like I say, what is the difference between talking with you on the phone over me seeing you?
	Telemedicine disadvantages	**Frustration with telemedicine**	It's hard to talk to him because when you talk on the computer, you have to press the button to talk to him
		Patient takes telemedicine less seriously	I think sometimes my daughter doesn't think it's as important, by doing the video
Other factors mediating preference	Patient condition	- Hospital in London is more efficient with tests - Less tests done for telemedicine	I'll probably get blood work and ultrasound there [in London]. But if it's just like check-ups … we can do here [through telemedicine].
	Testing factors	- More tests can be done in person - Prefers tests done in the same hospital	
	Weather	**Preference depends on the weather**	If the weather is good I don't sometimes mind going out to London … But in the winter or during worse weather I definitely prefer to stay in town and go for the appointment here
Prefers telemedicine			Well, there's almost no comparison it's so much easier doing the Tele-health appointment because it's not two airplanes and organizing our lives because we have two other children.
			It's so much easier doing the telehealth appointment because it's not two airplanes and organizing our lives because we have two other children. Personally, I prefer the telemedicine because just mainly for the reason that it takes hardly any time and I can get back to my everyday life.
Prefers in-person			Honestly, my daughter is so much happier when we're there [in person] and that it's despite the drive

Themes	Subthemes	Quotes
		Person-to-person is still the much preferred option. I feel like it's more personal scale. Like I think I understand it better like when I'm in the room with them.

Discussion

We are unaware of any previous study to directly assess pediatric patient preferences for telemedical consultations and contrast them with caregivers. We determined that preference for telemedicine for both patient and caregiver is dependent on consult-specific and context-specific factors, with patient diagnosis and weather conditions being the main modifying factors.

Significant differences existed in the preference of the location with slightly more adolescents favoring in person visits than their caregiver. We did not find a difference in the preference between telemedicine and tertiary care center if the patients lived more than 500 km away. This outcome might be partially due to younger patient's underestimation of the amount of time it takes to travel to the tertiary care center. Furthermore, younger patients may experience more confounding reasons for preferring in-person visits such as being able to miss school or spending the day out with the caregivers.

Overall, there was acceptance of telemedicine, and factors contributing to attitudes between patients and caregivers were largely congruent. Factors driving preferences for in-person visits were consult-specific, and factors driving preferences for telemedicine were context specific. Even though our quantitative results show no significant relationship between the patient's severity of illness and preference, our qualitative analysis shows that patient condition is still a strong mitigating factor contributing to preference of telemedicine vs. in-person visits. Patients with more complex conditions prefer in-person visits for a greater ease-of-mind; patient with less complex conditions believed that telemedicine was comparable to in-person visits. As there were no strong dislikes for telemedicine, one patient expressed strong favoring for all in-person visits due to the ability for close in-person contacts with the physician. Therefore, it is important to respect pediatric patient's attitudes when arranging telemedicine appointments to suit individual needs, especially for patients with more complex conditions. Most patients and caregivers agreed that having telemedicine as an option relieves stress and provides convenience. However, most participants expressed concerns with telemedicine due to technical difficulties of the video calls. Such disadvantages should be addressed as telemedicine may become increasingly popular. One caregiver mentioned that telemedicine is still an unfamiliar concept in her community, but she is very supportive of telemedicine and is advertising this technology to other parents in her community.

This initial study has a number of limitations. The patient group was heterogenous and may have suffered from selection bias. There were insufficient numbers in order for us to attempt to differentiate

experience with the health services and attitudes with telemedicine. Nonetheless, the data presented here demonstrate the complex aspects that affect the attitude towards telemedicine and highlights that the adolescents may have different attitudes towards telemedicine when compared to their caregivers.

Conclusions

Indiscriminate transfer to chronic care predicated on mainly telemedicine approach is not compatible with user expressed attitudes (especially patients). Understanding the preferences and perceptions of telemedicine, by users, is essential for best utilization of virtual care in the out-patient setting. Appreciation of the experiences and preferences of patients, relative to caregivers, will allow intelligent design and delivery of telemedical consultation in a way most appropriate to the kind of consultation. The study also shows that we need to encourage our youth to speak up about their preferences and respect that they may prefer in person visits over virtual encounters.

Abbreviations

OTN
Ontario Telemedicine Network

Declarations

Ethics approval and consent to participate: The study was approved by the Western's Human Research Ethics Board of the University of Western Ontario (file number 108400). Written informed signed consent/assent was obtained for all subjects from caregivers and written informed assent was obtained from consenting minors. Each participant gave written consent to publication of the results.

Availability of data and material: The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

Funding: The study was self-funded through discretionary research accounts of GF at Lawson Health Research Institute. The funding bodies had no role in the design of the study and collection, analysis, and interpretation of data and in writing the manuscript.

Competing Interests: The authors have no conflicts of interest relevant to this article to disclose.

Authors' Contributions: YQ conducted ½ of the interviews and transcribed them, extracted the nodes for the qualitative analysis, worked with the senior author on the quantitative analysis, helped with the drafts, provided vital intellectual input in the various versions and approved the final manuscript.

SC conducted the qualitative analysis, wrote major parts of the results, provided vital intellectual input in the various versions and approved the final manuscript.

CWM provided major intellectual input into the design of the study, helped with the design of the questions and the interpretation of the results, carefully edited and revised the various versions of the manuscript and approved the final manuscript.

BW conducted the other ½ of the interviews and transcribed them, helped with the drafts, added intellectual input to the paper, provided input in the various versions and approved the final manuscript.

GF conceived this project, obtained ethics approval over several versions, designed the questions, wrote the drafts, helped with the qualitative analysis and performed the quantitative analysis, made multiple edits, added intellectual content and approved the final version.

All authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

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Supplementary Files

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- AppendixAQuestionsVersion13Aug2017.docx