

## Parent-driven campaign videos: an analysis of the motivation and affect of videos created by parents of children with complex healthcare needs

### **Professor Bernie Carter,**

Professor of Children's Nursing  
Edge Hill University  
Faculty of Health & Social Care  
St Helens Road, Ormskirk, Lancashire, UK L39 4QP

Alder Hey Children's NHS Foundation Trust, Institute of Research  
Liverpool, Merseyside, UK

[bernie.carter@edgehill.ac.uk](mailto:bernie.carter@edgehill.ac.uk)

### **Dr Lucy Bray,**

Reader in Children, Young People & Families  
Edge Hill University,  
Faculty of Health & Social Care  
St Helens Road, Ormskirk, Lancashire, UK L39 4QP

Alder Hey Children's NHS Foundation Trust, Institute of Research  
Liverpool, Merseyside, UK

[brayl@edgehill.ac.uk](mailto:brayl@edgehill.ac.uk)

### **Dr Paula Keating**

Senior Lecturer in Children's Health  
Edge Hill University  
Faculty of Health & Social Care  
St Helens Road, Ormskirk, Lancashire, UK L39 4QP

[keatingp@edgehill.ac.uk](mailto:keatingp@edgehill.ac.uk)

### **Dr Catherine Wilkinson**

Lecturer in Children, Young People and Families  
Edge Hill University  
Faculty of Health & Social Care  
St Helens Road, Ormskirk, Lancashire, UK L39 4QP

Alder Hey Children's NHS Foundation Trust, Institute of Research  
Liverpool, Merseyside, UK

[Catherine.Wilkinson@edgehill.ac.uk](mailto:Catherine.Wilkinson@edgehill.ac.uk)

# Parent-driven campaign videos: an analysis of the motivation and affect of videos created by parents of children with complex healthcare needs

## Abstract

Caring for a child with complex health care needs places additional stress and time demands on parents. Parents often turn to their peers to share their experiences, gain support and lobby for change; increasingly this is done through social media. The WellChild *#notanurse but* is a parent-driven campaign that states its aim is to “shine a light” on the care parents, who are not nurses, have to undertake for their child with complex health care needs and to raise decision-makers’ awareness of the gaps in service provision and support.

This paper reports on a study that analysed the *#notanurse but* parent-driven campaign videos. The purpose of the study was to consider the videos in terms of the range, content and context, the perspectivity (motivation), and the affect (sense of being there) in order to inform the future direction of the campaign. Analysis involved repeated viewing of a subset of 30 purposively selected videos and documenting our analysis on a specifically designed data extraction sheet. Each video was analysed by a minimum of two researchers.

All but two of the thirty videos were filmed inside the home. A variety of filming techniques were used. Mothers were the main narrators in all but one set of videos. The sense of perspectivity was clearly linked to the campaign with the narration pressing home the reality, complexity and need for vigilance in caring for a child with complex health care needs. Different clinical tasks and routines undertaken as part of the child’s care were depicted. Videos also reported on a sense of feeling different to “normal families”; the affect varied amongst the researchers, ranging from strong to weaker emotional responses.

The lives of families of children with complex needs are largely hidden from the eyes of healthcare professionals, policy makers and other stakeholders. The *#notanurse\_but* campaign epitomises parent-driven advocacy, and whilst its focus is to illuminate the gaps in service provision and support, it also plays a role in raising awareness of wider issues such as the importance of a society that is fair to all its members.

## **Key Words**

Affect, complex healthcare needs, motivation, parent-driven campaign, parent-videos, perspectivity, social media, video analysis,

## **Introduction**

Caregivers of children who have a chronic illness experience both greater general and illness-related parenting stress than those caring for healthy children (Cousino et al. 2013). Caring for a child with health care needs and/or disability places additional stress (Bray et al, 2017) and time demands on parents who have to perform their usual parenting role alongside caregiving (nursing) tasks such as managing complicated medicine regimes, performing suctioning and administering parental feeding (McCann et al., 2012). The caregiving role means that many parents feel like they are 'on duty' all the time (Kvarme et al. 2016). Although some families receive nursing and other care-related support (Kirk et al., 2005), many parents receive insufficient support from health and social care professionals (Pelentsov et al., 2016).

Parents of children who have disabilities have reported that the sharing of experiences with other parents in a similar situation is important and useful to them both socially and emotionally (Shilling et al. 2013). This sharing of experiences can occur through one to one support (Nicholas & Keilty 2007) or through the use of social media platforms such as Facebook (Thoren et al., 2013), and use of videos via YouTube (Sampson et al., 2013) and Twitter (Mylod, 2015). This engagement with social media is unsurprising considering the massive increase in its use in recent years; the number of monthly active users of Twitter and Facebook is estimated to be 313 billion and 1.86 billion, respectively (Twitter, 2017; Facebook, 2016) and YouTube has over a billion users (YouTube 2017). In addition, online communities range from those such as Netmums (Russell, 2006) who provide broad parenting advice to communities providing condition-specific support (e.g., Tracheostomy UK Support), advice, information and connectivity (Oprescu et al 2013; Balkhi et al., 2013; Thoren et al., 2013; Stewart et al., 2011). Some of these communities, like NetMums, have a campaigning component to their role (Russell, 2006).

The health literature is notably lacking research reports of parent-initiated, parent-driven social media campaigns. However, Wittmeier et al. (2014) report on the 'Shit Happens' campaign launched by the mother of a child with Hirschsprung's Disease who worked with a marketing team to 'create the brand'. The campaign comprises a Facebook page, Twitter account and a blog which aims to support families living with Hirschsprung's Disease and raise awareness of the disease. The campaign has been successful in reaching families across the globe, which was its original intention, but does

not seem to have extended its reach to influence external stakeholders. Whilst there is considerable evidence that peer-to-peer support can create positive outcomes there is less research about the shift from being a 'support and exchange' community to becoming a force for external change.

Viewed overall, it appears that those external change initiatives that engage parents are ones which are part of community-based participatory research (Berge et al, 2009; GreenMills et al. 2013) or participatory action research initiatives which involve but are not led by parents (Walmsley & Mannan, 2009).

### **The WellChild *#notanurse\_but* campaign**

WellChild is a national charity in the UK that provides support to children with complex health care needs and to their families.

The *#notanurse\_but* campaign is a parent-driven campaign, that derives from parents self-identifying that they are “not a nurse but” in order to care for their child with complex health care needs at home, they have to undertake the sorts of care activities that would normally be the domain of nurses. These nursing activities include administering complex medication regimes, maintaining their child’s airway, putting their child onto overnight ventilation, urinary catheterisation, seizure management, adjusting oxygen delivery based on their child’s oxygen saturation levels and administering parenteral feeds. These tasks are undertaken alongside other roles such as assessing their child for pain and being alert for deterioration. The campaign was launched with the support of WellChild in November 2015 on Carers Rights Day with the aim of influencing key stakeholders such as commissioners of services, professionals and policy makers to improve support of and services for carers (Jones-Berry, 2015). A key part of this campaign are videos recorded by parents whose children receive support from WellChild; other aspects of the campaign include informal methods such as parents using social media to spread their message and more formal methods such as presenting at national child health conferences about their experiences. The videos aim to provide insight into those things that the parents think are important to share about their lives with their children with complex needs. The videos are uploaded and shared on various platforms including the WellChild website, the WellChild Families Facebook page, a dedicated *#notanurse\_but* Facebook campaign page, YouTube, Twitter and parents’ personal Facebook pages.

This paper reports on a small-scale study that aimed to analyse the *#notanurse\_but* campaign videos. The purpose of the study was to consider the videos in terms of the range, content and

context, the perspectivity (motivation), and the affect (sense of being there) in order to assist the parents and WellChild to determine the future direction of the campaign.

## **Methodology and Methods**

We used a qualitative, inductive approach for analysing the videos (Goldman et al., 2007) and have been guided by best analytical practices proposed for working with pre-existing video data (Barron & Engle 2007).

### **Method for Sampling Videos**

The dataset consisted of 47 videos generated for the campaign; some parents contributed one video, others contributed several; one mother contributed twelve. We purposively selected a subset of 30 videos to analyse. This selection was undertaken to ensure representation of all parents who had posted videos, the range and nature/content of video (based on the titles of the videos and an initial viewing of content) and the platforms the videos were posted on. We deemed each video to be a 'unit of analysis' with the start and end points being defined by the start and end of the video. The entirety of each video was viewed to reduce selection bias (Jewitt, 2012).

### **Ethics**

The study was approved by the Faculty of Health and Social Care Research Ethics Committee at Edge Hill University (FOH125); this committee acts in an equivalent way to an Institutional Review Board. The ethics framework governing health care research in the United Kingdom, meant that since the videos were publically available online, direct consent from the parents to view and analyse them from was not required. However, we were sensitive to using these videos as data when their original purpose had been as part of a campaign. Therefore, we gained specific assurance from the charity, and in particular from their Head of Family Services (responsible for liaison with families about the campaign), that parents were aware that the study had been commissioned and that videos would be selected for analysis. All due care was taken throughout the study in terms of being sensitive to any ethical issues (e.g., the content of the videos, the people appearing in the videos) as well as to research governance issues (e.g., storage and management of the analytical notes and the data extraction forms). Although this paper was written independently of WellChild, it was produced as part of contractual requirements from the charity as part of the research funding and in an effort to further disseminate the campaign. The parents who produced the videos were consulted by WellChild to gain their support for this aspect of dissemination and the parents reviewed the report the paper is based upon.

## **Data Analysis**

The research team consisted of three children's nursing academics and a social scientist; two of the team are parents. We developed a data extraction sheet for the study. The first draft of the data extraction sheet was used to extract data from four videos. Following a group discussion about the strengths and weaknesses of the data extraction sheet, we collapsed some fields, amended wording to help define the focus of what data should be recorded and added some new fields. The final data extraction sheet (see Figure 1) allowed us to map (identifying what is happening, who it is happening to), explore the 'sense of being there' (affect), macro-code (generate a timeline for key events in the video) and generate a narrative summary and transcription of selected key moments (see Barron & Engle 2007). The analysis from the first four videos was transferred onto the final data extraction sheet to ensure that analysis from all 30 videos was consistent.

Analysis involved repeated viewing of all 30 videos (including those we had piloted the data extraction sheet on) and documenting our observations on the revised data extraction sheet. As proposed by Barron and Engle (2007) we ensured that different viewpoints underpinned analysis as each video was viewed and analysed by two members of the research team; in addition, the Principal Investigator viewed all the videos. In order to develop a consistent approach to analysis, ten videos were each independently analysed by two researchers and each researcher produced an independent data extraction sheet for each video. These independent sheets were then discussed within a team meeting to identify issues, inconsistencies and ideas before a synthesis sheet was created for each video. For the remaining 20 videos we adopted an approach where one researcher took primary responsibility for the analysis and then passed their completed data extraction sheet to a second researcher who viewed the video and added their analysis to the sheet and also identified any areas of disagreement. These dual input sheets were also discussed at team meetings until we agreed that we had documented a complete record of our impressions and responses. We also watched some of the videos as a group to allow us to explore whether similar or different perspectives and phenomena were identified as proposed by Engle, Conant & Greeno (2007). The aim of this whole approach was to ensure that our findings were based on as complete a record as possible of the main content, themes, messages, perspectivity and sense of affect.

## **Findings**

The parents' names and the names of their children are presented in the findings as they are attached to the campaign videos and within the public domain.

The findings are presented in three main sections: range, context and content of the videos; perspectivity (motivation); and the affect (sense of being there).

### **Range, context and content**

We viewed 30 videos from 11 parents as follows: Leanne Cooper (n= 7); Jill Evans (n= 7); Faith Tutton (n=3); Craig Hatch (n=3); Hayley Smallman (n=3); Naomi Grosvenor (n=2); JennyBee (n=1); Lisa Schwarz (n=1); Louise Merrick (n=1); Sian Taylor (n=1); and Samantha Jayne Tolmie (n=1). The videos were accessed via the WellChild website, via Facebook (#*notanurse\_but* campaign page and WellChild page), YouTube and Twitter.

Thirty videos (75 minutes in total) were analysed between 12<sup>th</sup> October -10<sup>th</sup> December 2016 and all reported data below reflects this period of time. The duration of the videos was between 8 seconds – 9 minutes 52 seconds (average 2 minutes). The videos were published/posted between 20<sup>th</sup> November 2015 - 7<sup>th</sup> October 2016 (17 videos were posted in the first 2 months of the campaign; the remaining 13 posted between Jan-Oct, 2016). The number of views across all sites ranged from 20-2,500 (mean 648, median 487; at the low end of the range 7 videos had <100 views and at the high end, 6 videos had 1000-2000 views). The number of reactions such as likes, dislikes and emojis ranged from 0-63 likes (mean 2.1, median 6; 19 videos had fewer than 10 likes or positive emojis). The videos received 0-26 comments across all sites (mean 2.6, median 0; 17 videos had no comments. Although we intended to track 'shares' this was not possible to do effectively across the platforms so these data are not reported. Most of the responses on social media appeared to be from people who know the family (friends, relations), other 'WellChild families' and people in similar circumstances (e.g. parents of children with complex care needs). Most of these responses were affirmative of the parent being 'amazing' or 'strong' or saying that child is 'lovely' and 'brave' etc.

All but two videos were exclusively filmed inside the home. The rooms included appeared to be the living room/lounge, hall, kitchen, 'medical room', child's bedroom, parents' bedroom. There were some instances where it was unclear in which room the video was being filmed.

### ***Filming and editing techniques used***

A variety of different approaches were used in creating the videos. Most of the videos were planned and structured insights of a particular aspect of life or a skill but some of the videos were spontaneous, capturing an event as it unfolded. Some of the more structured videos used a mix of voice-overs, cutaways (images that showed something different to the main film), text, photographs and music. The videos seemed to have been either self-filmed (hand held selfie) or filmed by another

person. Some videos used a standardised *#notanurse\_but* campaign screen at the start of the video to signify clearly they were part of the campaign whereas others did not.

In some videos photographs were used, interspersed throughout the video content to portray more usual and expected aspects of 'normal' family life such as the children/family having fun, being together and being happy and showing the family taking part in activities outside of the home (e.g., in the playground, jacuzzi, swimming pool, car). Other photographs were included to provide a visual timeline (e.g., the birth of baby, child in hospital) and to reflect other settings that were relevant to the situation (e.g., respite centre, pharmacy).

### ***People featuring in and referred to in the videos***

In all but one set of videos the main narrator was the mother. Most videos included an introduction, "I'm X, mum of Y". A few videos did not have narrators but simply filmed what was happening. In some cases other people appeared in the film, either in person, or through the use of photographs or were referred to by name. Some videos introduced us to the child with complex health care needs and provided a medical history/set of diagnoses; others did not do this. Often the person filming remained anonymous. The people included in the videos either in person or indirectly through photographs or being referred to included: the narrator (mother or father); their partner; the child with complex needs; their child's siblings; grandmother, carers (including school bus carers/drivers); and other people (unclear of specific role) within a respite setting.

### **Perspectivity (motivation for creating the videos)**

Although the videos covered a wide range of issues, the sense of perspectivity (motivation for creating the videos) was clearly the *#notanurse\_but* campaign, as Leanne who generated the idea for the campaign explains in one of her videos:

So I approached WellChild and basically said 'My family – our story - it's basically not unique. There are 1000s of families like my own, facing the same daily struggles, delivering the same and many different medical procedures at home.' So it's about highlighting...to all the decision makers and society itself...the lengths we go to keep our children safe and well at home... If we don't stand up, if we don't talk now, if we don't share these experiences, how are going to make that positive changes, how are we going to make people listen and want to make those changes. One voice can't do it alone but there are 1000s of you out there that can help support us and WellChild. WellChild can help us get the stories out there. Don't be afraid. Just share your story. (Leanne)

Hayley also talked in one of her videos of the importance of the campaign, explaining that:



“The not a nurse but campaign is important to us as we really want to shed a light on the reality of the work that goes into keeping a child like Holly with such complex health care needs at home and allowing her to live a fulfilled and happy life.” (Hayley)

The parents’ key message was that they had to perform clinical tasks they had never expected to do. The extent of the clinical tasks the parents performed was evident in the videos, as was the responsibility of getting things right for their child. There were three main areas that were addressed to communicate their message: routines, preparation and procedures; being vigilant and making decisions; and impact on family life - feeling and being different.

### ***Routines, preparation and procedures***

The videos presented a range of different tasks including giving medicines (throughout day/night) (n=15), ventilator related tasks (n=10), suction (n=8), feeding (primarily via parental route) (n=11), collecting data for a sleep study (n=1) and changing tracheostomy tapes (n=1). Videos (n=8) associated with routines included ‘morning routine’ that addressed the work involved in waking the child (and their siblings) and the challenge of getting clinical tasks done as part of the getting ready for school/work routine. In his video Craig explained part of his son’s morning routine:

“This is Fraser, just awake.... you’re not very happy, you’re sore in the morning, aren’t you Fraser? This is Fraser getting ready for the day. First thing we do is we give him his medications which go in through a tube in his stomach – a button in his stomach - so we need to be careful about how these go in. Then once all the first tranche of medications, medicines have gone in, we have to rinse through the button.” (Craig)

It was also clear from the videos that the parents had to be awake and caring much earlier in the morning than many parents without a child with complex health care needs. Night time routines (n=11) involved the care provided in getting the child ready for bed as well as the challenges of regularly having to be awake during the night to care for their child. Faith talked of providing care through the night:

“Sophie has been awake since 3 o’clock this morning, since giving her extra sedative at 4 she’s now gone back to sleep, so I now need to creep into her bedroom and put these down her gastrostomy tube without waking her up” (Faith)

Videos (n=13) also demonstrated the need to be constantly prepared/organized by showing parents stocking up on medical supplies, using checklists and one video showing the mother keeping a diary of their child’s condition throughout the day. It was clear from the videos that the routines were

“relentless” and the consequences of the routine slipping was evident in some videos (n=2), as Sian explains:

“Olly’s actually on three medications, they are all very powerful and very very strong medications which are attempting to control the seizures but it doesn’t eliminate them. So any slip in the routine with administering the drugs or even if he spits it out or refuses to take it from the syringe one day or vomits or has an upset stomach can have a major consequences to his stability and start of a whole pattern of increased seizure activity.” (Sian)

### ***Being vigilant and making decisions***

In some of the videos (n=13) the parents were emphasising how important it is to be vigilant and attentive to their child’s needs so that they could either prevent or deal with crises. Jill explained:

“if things [oxygen saturation levels] up towards 95 then we’ll leave him and if they’re dipping lower than 90 then we’ll add oxygen in... at the moment he’s doing great, no more need for anything extra. I can have my tea and we’ll sit and watch him for the night until the carer comes” (Jill)

Parents talked about the need to listen to their child’s breathing to determine if they were “bubbly” or “rattly” as well as to check whether their child’s “sats were dropping” or if they had a “temperature”. Jill made a video about her son’s ventilator which had malfunctioned “all the water had flooded through the dome and into both lots of tubing and actually right up through the filter and into the ventilator”. Parents were aware that vigilance was coupled with a need to be able take action based on good and timely decisions such as “when to start antibiotics, call for help.... you can never really tell”.

### ***Feeling and being different***

Many videos (n=28) emphasised the differences between the life of a child with complex health care needs and the lives of their brothers and sisters and/or the lives of their own family with “normal families” (families who were not caring for a child with complex health care needs). Juggling family life was seen to be a challenge and one mother explained that trying “to be mummy” whilst providing high level technical care “is a real tricky *#notanurse\_but* thing”. In the videos examples of differences between their families and “normal’ families” included “real food” versus parental feeds and a simple school bag was compared to the bags of equipment needed to accompany the child with complex health care needs to school. Some videos (n=5) filmed around Christmas time drove home the sense of being different; one video showed how one child in the family had chocolate in their Christmas stocking, whilst the child with complex needs would be getting a routine bolus of

vitamin water. Other videos (n=6) showed the differences in terms of how space in the home was appropriated by medication, supplies and equipment.

The language used by parents in describing what was happening and the messages they were trying to convey reflected that they were different to “normal families”. They were fluent in terminology that may not be easily understood by some viewers (e.g., sats machine, trachy, vent. etc.). In some videos (n=3) the child’s siblings also demonstrated fluency in clinical terminology (e.g., “hypo” and “high tone”) and the ability to step in to provide the sort of care you would not usually expect a child to give. Ruby, who was 8 years old, explained that “sometimes when my mum has to get a shower, I have to do Holly’s suction.”

Other, perhaps unplanned or unintentional aspects of the videos were apparent, for example, the visible differences in the child’s body (scars, dressings, different position/mobility) serving to remind the viewer of differences between children with complex health care needs and other children.

### **Affect (‘sense of being there’)**

The affect of the videos on us as viewers varied between the members of the team. Some videos had a strong impact; others less so and the affect will undoubtedly have been influenced by the fact we were viewing the videos for a specific analytical purpose. Also, as an audience we were likely to be atypical of the intended audience (although the campaign is not completely explicit on who the intended audience is). Three members of the research team are nurses and two of these are parents, however none of us is/has been the parent of a child with complex health care needs. It was clear to the team that videos were a powerful way of the parents authentically showing aspects of what day and night life is like on a daily basis for the children, their parents and brothers and sisters. Videos showing parents caring for their children and undertaking complex medication regimes at night and managing crisis with ventilators shed a light on the reality of the care required and of the work, skills and knowledge involved in keeping their child at home. Where simply listening to parents talk about their experiences may have created a sense of affect, viewing the video meant we were able to see how tired and how worried the parents seemed and the skilful way they cared for their child. The videos allowed us entry into the lives of the parents; we met them at the start and the end of the day, we saw in their work clothes and their pyjamas, in their Christmas finery and their everyday clothes; this added to the affect.

## Discussion

Family life is dominated and disrupted by the many-faceted, clinical caregiving roles the parents have to adopt. The fact that this occurs without adequate support or resources to support the parents is the fundamental driver for *#notanurse\_but* campaign. Despite this, the parents in the videos express a heartfelt desire for their children to be at home and part of the family because this is where their children “belong”. There is an inherent tension in children with such complex health care needs being at home and the demands that this brings (Moran, Spittle et al., 2015); and there is considerable evidence that the services available to provide support to the families is insufficient to meet their needs (Carter, Coad et al., 2012). Other studies have explored these facets of life at home with a child with complex needs (Kirk et al., 2005; Kvarme et al., 2016). Many authors report parents’ having similar experiences to the ones portrayed in the videos, where parenting is raised to a different level when caring for a child with complex health care needs. Various terms have been used to portray this including vigilant parenting (Woodgate et al., 2008), expert parenting (Kirk & Glendinning, 2002), intense parenting (Woodgate et al., 2015) and extraordinary (Carter & Bray, 2016). Even when parents’ voices are generated through high quality qualitative research such as is evident in the previous studies, the lives of the parents and their families are represented through written reports in which the individual context has been fragmented and somewhat stripped. Reading the evidence about the challenges of dealing with the bone-tiredness of broken nights of sleep (McCann et al. 2015; Kielty et al., 2015) is absolutely different to seeing exhausted, tousled parents in dressing gowns, drawing up complex medication regimes in the very early morning. The videos have an impact that text alone does not capture.

The lives of families of children with complex needs are largely hidden from the eyes of health care professionals, commissioners, policy makers and other stakeholders. Social media offers an accessible way for people to connect, gain support and share information (Wittmeier et al., 2014; Thoren et al., 2013). Social media also provides a democratic, bottom-up way for people to lobby for change by extending their reach and giving them the chance to influence change agents. Mylod (2015), for example, reports on the success of the *@heartmummy#hospitalbreastfeeding* Twitter campaign that has “united service user and professional voices” in improving breastfeeding support within neonatal and children’s hospital settings.

The parent-driven campaign reported in this study was focussed on parents telling and sharing their stories about the “daily struggles” in decision making and providing clinical and other care to their children with complex health care needs. The campaign is a call to various stakeholders (including other parents whose children have complex health care needs) as well as to the “decision makers”

and to “society” to help make “positive changes” to support parents to keep their children “safe and well at home.” There is a strong sense that the campaign is rooted in both the child’s right to be cared for at home and for the family to have the right not to have to be constantly vigilant, and undertake roles that are physically and emotionally challenging. The need for social justice is evident and the campaign can be seen as a powerful extension of the advocacy that parents of children with complex health care needs have to enact at an individual level on a day-to-day basis (Bray et al., 2017), as also seen in studies of parents of children with autism (Boshoff et al., 2016). Their actions through the campaign are starting to challenge the status quo where society and service providers appear to see it is reasonable to expect parents, with little professional and/or emotional support, to provide highly technological clinical care and to be vigilant to changes and deteriorations in their child’s condition. The use of the videos and the reach of social media is a means of empowering the parents to act as advocates for other parents who are ‘not nurses’ but expected to take on the role of nurses. The *#notanurse\_but* campaign epitomises Holcomb-McCoy and Bryan’s (2010, p263) definition of advocacy “as consisting of organised actions to highlight critical issues that have been ignored and submerged, to influence public attitudes, and to enact and implement laws and public policies so that visions of what should be in a ‘just, decent society’ become a reality”.

The videos show those facets of everyday life that the parents thought were important to publically share without any direction from a researcher and without any of the ethical constraints that may or may not have shaped other experience-based studies. It is highly likely that the videos (data) that have been posted on the WellChild website will have been filtered by the parents (e.g., first takes may have been deleted, videos that did not convey the tone or message they wanted may never have been uploaded). However, to all intents and purposes these videos are the direct voices of the parents speaking out to other parents, to other stakeholders, interested parties and decision-makers. The technical competence underpinning the videos is varied but despite this most tell a clear story using a simple format that shows the differences between ‘ordinary’ family life and their own. Although the narrators of many of the videos directly used the *#notanurse\_but* ‘tag’, mentioned the *#notanurse\_but* campaign or used text and logos to accompany the videos, it would not necessarily have been clear to some viewers what the campaign was about. This and other factors such as the lack of ‘branding’ in some videos, may have impacted on the reach of the campaign as has been seen in the analysis of other YouTube video campaigns (Arroyo Almaraz et al., 2013).

Dorfman et al. (2002) talk of the concept of campaign maturity and it is likely that considering the relatively small number of videos developed over a relatively wide time span neither the campaign

nor the issue have yet reached maturity or infiltrated the public consciousness. Dorfman et al. maintain that issues (in this case the expectations that parents should not have to manage technological care with little support) take time to mature and to infiltrate the public consciousness. If using Dorfman et al.'s taxonomy of campaigns, the *#notanurse\_but* campaign would best be considered as aiming for policy change but impacting more on behaviour change (e.g., commissioners of services acting to provide improved support). Whilst the parents are aiming for a large scale and broad influence, based on the metrics we considered (e.g. the number of views, retweets and shares), the impact of the campaign is still relatively modest. In terms of Dorfman et al.'s taxonomy this would position the campaign as being a young and informal rather than an established campaign. This analysis shows that while the *#notanurse\_but* campaign is at the start of making change, it perhaps needs more support to increase online viewership, engagement and reach. Key to this would be a more strategic use of social media, for example, increasing the videos' ranking on YouTube. The algorithm that underpins ranking on YouTube reflects 'watch time' (the amount of time a viewer watches the video) (YouTube Analytics, 2017) and 'watch time' affects the stability and acceptability (Fernandez-Llatas, 2017). Other strategies include ensuring that appropriate key health and clinical terms are used in the metadata associated with the video (e.g., titles and accompanying text) (Bocanegra et al., 2017), as this would assist search engines locate the videos, increasing 'findability'. Another issue for potential viewers is filtering the vast amount of misleading and incorrect video material on the internet (Madathil 2015) and sources that lack credibility (Desai et al., 2013) from credible information. The *#notanurse\_but* campaign videos have the advantage of being linked to WellChild, a credible organisation that provides the context for the campaign.

Madathil et al (2015) note the deficit in research focusing on interventions for effective dissemination of healthcare videos and the *#notanurse\_but* campaign videos occupy a somewhat different position to the types of videos that generally gain researchers' attention. These videos do not fall into a neat category, they are not purely educational although viewers can learn from them, they are campaigning but not advertising and they are not entertainment. Social networking is fundamental to the diffusion of user-generated content (Susarla et al., 2012) and it has been key to the *#notanurse\_but* campaign; this has been achieved through the parents' individual social networks (family, friends, colleagues, associations) and via WellChild and its social networks (e.g., other families, charities, politicians, professionals).

### **Limitations and implications for future research**

We are aware that the approach utilised (i.e., the research team acting as the only audience for the material) is limited compared to having a much more diverse audience (e.g., other parents of children with complex health care needs, commissioners of services, politicians, health care professionals). However, engagement with a wider audience was beyond the scope and funding of this study.

In this case, utilising extant materials provided the research team with a set of videos that the parents had chosen to record. The researcher is both present and absent. However, demographic data that would usually be routinely collected (for example, ethnic background, medical history, socio-economic situation) are either unavailable or can only be implied from observing and listening to the videos. These data, if thought to be important, could potentially be generated by directly contacting the families. We chose not to do this as we might have been contacting a family during a difficult time.

Future research should build on the foundation of this study but should consider incorporating a wider range of participant viewers and continue to develop the opportunity to engage with the parents who made the videos to determine if our interpretation aligns with their intent. Engaging with a wider range of stakeholders could occur in different ways, for example, setting up a booth at a major conference and encouraging delegates to watch the videos and capturing their perspectives, taking the videos to parent/family support groups and generating discussion or promoting discussion of the videos through webinars.

### **Conclusion**

Campaigns are “like icebergs, partly visible and mostly hidden” (Dorfman et al. 2002, p40); this was the case with this campaign. The videos created by the parents are a visible part of their efforts to make change happen but it seems clear that they could be more visible (e.g., by establishing a higher ranking in YouTube Fernandez-Llatas, 2017) which in turn would extend their reach and influence. Although the parents aim to reach policy makers, adopting an approach that specifically targets policy makers and commissioners of service could be a valuable way of strengthening and extending its current reach. Creating the videos has provided parents with the opportunity to share authentic insights into their everyday lives and the challenges they face. The use of a campaign raises the profile of the videos, generates a strong sense of advocacy and builds the call for more support and resources for children with complex needs and their families.

## Declaration of interest

The authors report that the study was partially funded by WellChild but that the analysis was undertaken and the paper was written independently of any oversight from WellChild. The authors gained no financial benefit from undertaking the study.

## References

- Arroyo Almaraz, I., Banos Gonzalez, M., & Van-Wyck, C. (2013). Analysis of the campaign videos posted by the Third Sector on YouTube. *Revista Latina de Comunicacion Social*, 328. doi:10.4185/RLCS-2013-980en
- Balkhi, A. M., Reid, A. M., McNamara, J. P., & Geffken, G. R. (2014). The diabetes online community: The importance of forum use in parents of children with type 1 diabetes. *Pediatric Diabetes*, 15(6), 408-415. doi:10.1111/pedi.12110
- Barron, B. & Engle, R.A. (2007) Analysing data derived from video records. In: Derry, S.J. *Guidelines For Video Research In Education: Recommendations From An Expert Panel*. Data Research and Development Center Chicago.
- Berge, J. M., Mendenhall, T. J., & Doherty, W. J. (2009). Using community-based participatory research (CBPR) to target health disparities in families. *Family Relations*, 58(4), 475-488. doi:10.1111/j.1741-3729.2009.00567.x
- Boshoff, K., Gibbs, D., Phillips, R. L., Wiles, L., & Porter, L. (2016). Parents' voices: 'why and how we advocate'. A meta-synthesis of parents' experiences of advocating for their child with autism spectrum disorder. *Child: Care, Health and Development*, 42(6), 784-797. doi:10.1111/cch.12383
- Carnevale, F.A., Alexander, E. Davis, M., Rennick, J. & Troini, R. 2006. Daily Living with Distress and Enrichment: The Moral Experience of Families with Ventilator-Assisted Children at Home. *Pediatrics* 117 (1): e60. [www.pediatrics.org/cgi/doi/10.1542/peds.2005-0789](http://www.pediatrics.org/cgi/doi/10.1542/peds.2005-0789).
- Carter, B., & Bray, L. (2016, Nov 24). How caring for a child with complex health needs can be both isolating and extraordinary. The Conversation Retrieved from <https://theconversation.com/how-caring-for-a-child-with-complex-health-needs-can-be-both-isolating-and-extraordinary-66651>
- Bray, L., Carter, B., Sanders, C., Keegan, K. Parent-to-parent peer support for parents of children with a disability: A mixed method study. *Patient Education and Counseling*. Published online..
- Carter, B., Coad, J., Bray, L., Moore, A. Anderson, C., Clinchant, A., Widdas, D. & Goodenough, T. 2012. "Home-Based Care for Special Healthcare Needs: Community Children's Nursing Services." *Nursing Research* 61 (4): 260-268.
- Cousino, M. K., & Hazen, R. A. (2013). Parenting stress among caregivers of children with chronic illness: A systematic review. *Journal of Pediatric Psychology*, 38(8), 809-828. doi:10.1093/jpepsy/jst049
- Derry, S.J. (2007) *Guidelines for video research in education. Recommendations from an expert panel*. Data Research and Development Center Chicago.<http://drdc.uchicago.edu/what/video-research-guidelines.pdf>.
- Desai, T, Shariff, A, Dhingra, V, Minhas, D, Eure, M, & Kats, M 2013, 'Is Content Really King? An Objective Analysis of the Public's Response to Medical Videos on YouTube', *Plos ONE*, 8, 12, pp. 1-6, Academic Search Premier, EBSCOhost, viewed 1 July 2017.
- Dorfman, L., Ervice, J., & Woodruff, K. (2002). Voices for change: A taxonomy of public communications campaigns and their evaluation challenges. Berkeley, CA.: Berkeley Media Studies Group.



- Engle, R. A., Conant, F. R., & Greeno, J. G. (2007). Progressive refinement of hypotheses in video supported research. In R. Goldman, R. Pea, B. Barron, & S. J. Derry (Eds.), *Video Research in the Learning Sciences*. Mahwah, NJ: Erlbaum: 239-254.
- Fernandez-Llatas, C., Traver, V., Borrás-Morell, J-E., Martínez-Millana, A. & Karlsen, R. Are Health Videos from Hospitals, Health Organizations, and Active Users Available to Health Consumers? An Analysis of Diabetes Health Video Ranking in YouTube. *Computational and Mathematical Methods in Medicine*. Article ID 8194940. <https://doi.org/10.1155/2017/8194940>
- Facebook. (2014). Facebook Newsroom. Retrieved 30 April 2014 from <http://newsroom.fb.com/company-info/> (Facebook, December 31, 2014; accessed today 3/23/15)
- Goldman, R., Erickson, F., Lemke, J. and Derry, S. (2007) Selection in video. In: Derry, S. (ed) *Guidelines For Video Research In Education: Recommendations From An Expert Panel*. Data Research and Development Center: 19 – 27.
- Goldman, R. (2009) Video representations and the perspectivity framework. In: Goldman, R., Pea, R., Barron and Derry. *Video Research in the Learning Sciences*. Routledge: New York: 3-38.
- GreenMills, Lisa L., Kirsten K. Davison, Karen E. Gordon, Kaigang Li, and Janine M. Jurkowski. 2013. "Evaluation of a Childhood Obesity Awareness Campaign Targeting Head Start Families: Designed by Parents for Parents." *Journal of Health Care for the Poor and Underserved* 24 (2): 25-33. doi:10.1353/hpu.2013.0096.
- Holcomb-McCoy, C., & Bryan, J. (2010). Advocacy and empowerment in parent consultation: Implications for theory and practice. *Journal of Counseling & Development*, 88(3), 259-268. doi:10.1002/j.1556-6678.2010.tb00021.x
- Jewitt, C. (2012) *An introduction to using video in research*. National Centre for Research Methods Working Paper 03/12.
- Jones-Berry, S. (2015). Social media campaign highlights lack of expert care provision for parents. *Nursing Children and Young People*, 27(10), 7. doi:10.7748/ncyp.27.10.7.s6
- Keilty, K., Cohen, E., Ho, M., Spalding, K., & Stremler, R. (2015). Sleep disturbance in family caregivers of children who depend on medical technology: A systematic review. *Journal of Pediatric Rehabilitation Medicine*, 8(2), 113-130. doi:10.3233/PRM-150325.
- Kirk, S., Glendinning, C. & Callery, P. (2005). Parent or Nurse? the Experience of being the Parent of a Technology-Dependent Child. *Journal of Advanced Nursing*, 51 (5): 456-464.
- Kvarme, L. G., Albertini-Früh, E., Brekke, I., Gardsjord, R., Halvorsrud, L., & Liden, H. (2016). On duty all the time: Health and quality of life among immigrant parents caring for a child with complex health needs. *Journal of Clinical Nursing*, 25(3-4), 362-371. doi:10.1111/jocn.13056
- Madathil, K.C., Rivera-Rodriguez, A.J., Greenstein, J.S. & Gramopadhye, A.K. 2015, "Healthcare information on YouTube: A systematic review", *Health Informatics Journal*, vol. 21, no. 3, pp. 173-194.
- McCann, D., Bull, R., & Winzenberg, T. (2012). The daily patterns of time use for parents of children with complex needs: A systematic review. *J Child Health Care*, 16(1), 26-52.
- McCann, D, Bull, R., and Winzenberg, T. 2015. "Sleep Deprivation in Parents Caring for Children with Complex Needs at Home: A Mixed Methods Systematic Review." *Journal of Family Nursing* 21 (1): 86-118.
- McCann, D., Bull, R., & Winzenberg, T. (2016). Brief report: Competence, value and enjoyment of childcare activities undertaken by parents of children with complex needs. *Journal of Pediatric Nursing*, 31(2), e132. doi:10.1016/j.pedn.2015.10.018
- Moran, F.C., Delany, C., & Spittle, A.J. (2015). Lifestyle Implications of Home Mechanical Insufflation-Exsufflation for Children with Neuromuscular Disease and their Families. *Respiratory Care* 60 (7): 967-974.
- Mylod, D. (2015). Breast feeding a sick child; can social media influence practice? *Issues in Comprehensive Pediatric Nursing*, 38(2), 77-84. doi:10.3109/01460862.2015.1009584
- Nicholas, D. B., & Keilty, K. (2007). An evaluation of dyadic peer support for caregiving parents of children with chronic lung disease requiring technology assistance. *Social Work in Health Care*, 44(3), 245-259. doi:10.1300/J010v44n03\_08

- Oprescu, F., Campo, S., Lowe, J., Andsager, J., & Morcuende, J. A. (2013). Online information exchanges for parents of children with a rare health condition: Key findings from an online support community. *Journal of Medical Internet Research*, 15(1), e16.
- Pelentsov, L. J., Fielder, A. L., & Esterman, A. J. (2015). The supportive care needs of parents with a child with a rare disease: A qualitative descriptive study. *Journal of Pediatric Nursing*, 31(3), e218. doi:10.1016/j.pedn.2015.10.022
- Pelentsov, L. J., Fielder, A. L., Laws, T. A., & Esterman, A. J. (2016a). The supportive care needs of parents with a child with a rare disease: Results of an online survey. *BMC Family Practice*, 17, 88. doi:10.1186/s12875-016-0488-x
- Pelentsov, L. J., Laws, T. A., & Esterman, A. J. (2015). The supportive care needs of parents caring for a child with a rare disease: A scoping review. *Disability and Health Journal*, 8(4), 475-491. doi:10.1016/j.dhjo.2015.03.009
- Russell, S. (2006). Netmums: Online support for parents. *Community Practitioner: The Journal of the Community Practitioners' & Health Visitors' Association*, 79(2), 44.
- Sampson, M., Cumber, J., Li, C., Pound, C. M., Fuller, A., & Harrison, D. (2013). A systematic review of methods for studying consumer health YouTube videos, with implications for systematic reviews. *PeerJ*, 1, e147. doi:10.7717/peerj.147
- Shilling, V., Morris, C., Thompson-Coon, J., Ukoumunne, O., Rogers, M. & Logan, S. 2013. "Peer Support for Parents of Children with Chronic Disabling Conditions: A Systematic Review of Quantitative and Qualitative Studies." *Developmental Medicine and Child Neurology* 55 (7): 602-609.
- Stewart, M., Letourneau, N., Masuda, J. R., Anderson, S., & McGhan, S. (2011). Online solutions to support needs and preferences of parents of children with asthma and allergies. *Journal of Family Nursing*, 17(3), 357-379. doi:10.1177/1074840711415416
- Susarla, A., Oh, J. & Tan, Y. 2012, "Social Networks and the Diffusion of User-Generated Content: Evidence from YouTube", *Information Systems Research*, vol. 23, no. 1, pp. 23-41.
- Thoren, E. M., Metze, B., Bührer, C., & Garten, L. (2013). Online support for parents of preterm infants: A qualitative and content analysis of facebook 'preemie' groups. *Archives of Disease in Childhood.Fetal and Neonatal Edition*, 98(6), F538. doi:10.1136/archdischild-2012-303572
- Twitter. (2017). About Twitter. Retrieved 16 February 2017 from <https://about.twitter.com/company>
- Wallsten, K. (2010). "Yes we can": How online viewership, blog discussion, campaign statements, and mainstream media coverage produced a viral video phenomenon. *Journal of Information Technology & Politics*, 7(2-3), 163-181. doi:10.1080/19331681003749030
- Walmsley, J., & Mannan, H. (2009). Parents as co-researchers: A participatory action research initiative involving parents of people with intellectual disabilities in Ireland. *British Journal of Learning Disabilities*, 37(4), 271-276. doi:10.1111/j.1468-3156.2009.00582.x
- Wittmeier, K., Holland, C., Hobbs-Murison, K., Crawford, E., Beauchamp, C., Milne, B., Keijzer, R. (2014). Analysis of a parent-initiated social media campaign for Hirschsprung's disease. *Journal of Medical Internet Research*, 16(12), e288.
- Woodgate, R.L., Ateah, C. & Secco, L. 2008. Living in a World of our Own: The Experience of Parents Who have a Child with Autism. *Qualitative Health Research* 18 (8): 1075-1083. doi:10.1177/1049732308320112.
- Woodgate, R.L., Edwards, M., Ripat, J.D., Borton, B., & Rempel, G. (2015). Intense parenting: A qualitative study detailing the experiences of parenting children with complex care needs. *BMC Pediatrics*, 15(1) doi:10.1186/s12887-015-0514-5
- YouTube (2017a) Statistics. <https://www.youtube.com/yt/press/en-GB/statistics.html>. Accessed 30<sup>th</sup> June 2017.
- YouTube (2017b) Watch-time reports. [https://support.google.com/youtube/answer/1714329?hl=en&ref\\_topic=3029003](https://support.google.com/youtube/answer/1714329?hl=en&ref_topic=3029003) Accessed 30<sup>th</sup> June 2017.