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Abstract

A new group of medically fragile young adults are graduating from pediatric palliative care programs with limited expectations to live beyond early adulthood, and no comparable adult services to support their complex needs. Accessing this population is difficult because of the complexity of their conditions, the extensive personal and equipment supports that limit feasibility for travel, and divergent communication abilities. Therefore, we undertook a descriptive case study using an asynchronous modification of an online focus group, a bulletin board focus group (BBFG). The greatest strengths of the BBFG are the appeal of this methodology for young adults and the multi day focus group becomes both a community and an intervention. An important limitation of this method was participant follow through on discussion threads. This BBFG provided rich and varied types of data, and very positive participant experiences.

Keywords

Bulletin Board Focus Group, Case Studies, Complexity, Disability/Disabled Persons, End-Of-Life Issues, Focus Groups, Illness and Disease, Young Adults

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Innovations in Research with Medically Fragile Populations: Using Bulletin Board Focus Groups

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A new group of medically fragile young adults are graduating from pediatric palliative care programs with limited expectations to live beyond early adulthood, and no comparable adult services to support their complex needs. Accessing this population is difficult because of the complexity of their conditions, the extensive personal and equipment supports that limit feasibility for travel, and divergent communication abilities. Therefore, we undertook a descriptive case study using an asynchronous modification of an online focus group, a bulletin board focus group (BBFG). The greatest strengths of the BBFG are the appeal of this methodology for young adults and the multi day focus group becomes both a community and an intervention. An important limitation of this method was participant follow through on discussion threads. This BBFG provided rich and varied types of data, and very positive participant experiences. Keywords: Bulletin Board Focus Group, Case Studies, Complexity, Disability/Disabled Persons, End-Of-Life Issues, Focus Groups, Illness and Disease, Young Adults

While advances in pediatric health care and technology have extended the life span for some medically fragile young adults with pediatric life threatening conditions, there are no comparable adult health and social services to support their complex needs (Doug, Adi, Williams, Paul, Kelly, Petchey, & Carter, 2011; Hamdani, Jetha & Norman, 2011; Stewart, Stavness, King, Antle, & Law, 2006). The philosophical differences between pediatric and adult palliative care exclude this population from adult palliative care services, very little research has focused on the experiences of young adults who have transitioned (Fletcher-Johnson, Marshall, & Straatman, 2011), and there is no evidence in the literature of transition experiences of youth “aging out” of pediatric palliative care (Doug et al.). Therefore, these young adults transition out of a comprehensive and supportive pediatric palliative care program into an environment with no specific care delivery system in either palliative or chronic care services. This gap leaves them striving to achieve young adult developmental milestones within a compressed time frame, while navigating new health, education and social systems that provide fewer supports (Meleis, Sawyer, Im, Hilfinger, Messias, & Schumacher, 2000; Prestidge, Romann, Djurdjev, & Matsuda-Abadini, 2012; Rogers, 1997).

Our research goal was to understand the experiences and perceptions of individuals within this population, however, there are significant challenges using traditional methods of qualitative data collection, such as interviews or focus groups. Accessing this population is difficult because of the complexity of the individuals’ conditions, their limited mobility to travel and commit to specific interview times, and divergent communication abilities due to

weakness, that lead to the use of computer mediated voice recognition, typing or speech. Most of these individuals require 24-hour attendant care, and their independent function can be reduced to minimal movement of their index finger on a joystick to control power wheel chairs, computers and phones. Because of the sensitivity of the topics discussed with this group and the complexities of their condition, we selected research strategies that would provide meaningful data while remaining mindful of participant communication limitations, and ethical issues that could arise with new research modalities. Because loneliness and isolation are common experiences for those without work or school opportunities, this research method provided the added benefit of a social connection with their peers.

To address these specific methodological challenges, we undertook a descriptive case study (Yin, 2009), using a Bulletin Board Focus Group (BBFG), with the purpose of examining the complexity of factors affecting the transition experiences of young adults with pedLTC to adult services. Bulletin board focus groups (BBFG) are an asynchronous modification of an online focus group. The BBFG conversation is carried on over several days instead of in a single session, allowing participants to log in and out of the discussion when it is convenient for them. Unlike many qualitative techniques that favour those with quick responses (typically extroverts), the asynchronous BBFG creates advantages for those who are less spontaneous. Some question types require more extended thinking, and results can be improved when participants can take time to reflect before answering (Abbott, 2011). This proved especially true of questions relevant to this study, such as thoughts about the future, intimacy, and end of life preparation and preferences.

In this paper, we describe how the innovative BBFG methodology facilitated access to this medically fragile population, provided a rich qualitative understanding of their experiences and offered benefits to the participants. This research involved medically fragile young adults with pedLTC, not expected to live beyond their first decade of adulthood (19-29 years). A purposeful sample of English speaking young adults with pedLTC, such as DMD, or Spinal Muscle Atrophy (SMA), who were cognitively capable to participate in a BBFG, from the graduates of a children's palliative care program in western Canada were selected. Two groups of four young adults participated in this five-day BBFG supported by iTracks™, a Canadian software company. The primary investigator is a nurse and clinical counsellor with more than ten years' experience with youth and families managing chronic and palliative conditions, and this study was reviewed and approved by two university ethical review boards. An audit trail of the research process was maintained.

Overview and Rationale of BBFGs with Medically Fragile Populations

Overview

The following section describes the research opportunities that online focus groups offer that cannot be realized with face-to-face interviews or focus groups with medically fragile populations. First, an online format connects individuals geographically disparate from each other (Cantrell & Lupinacci, 2007; East, O'Brien, Jackson, & Peters, 2008; Fox, Morris, & Rumsey, 2007; Kralik, Price, Warren, & Koch, 2006; Stewart & Williams, 2005) and those requiring personal support, suitable and timely transportation, and well-functioning equipment, to attend a face-to-face meeting. Second, within this group of young adults, many are losing the ability to type (even with technological aids) or to speak clearly. The BBFG format provides the option to choose either text or webcam methods to participate.

Third, BBFGs reduce inhibitions, so that participants report more freedom to respond candidly to sensitive topics (Campbell et al., 2002; East et al., 2008; O'Connor & Madge, 2003). This was an important consideration for conversations discussing intimacy and end of

life with young adults. For many, their appointments with health care professionals have always been (and can still be) in the company of their parents, and they likely have not been provided with the privacy to discuss some of their questions and concerns. Finally, teens and young adults are empowered in online formats to be more assertive and confident in their interactions with an adult facilitator than in face-to-face groups. Their confidence and fluency in online social interactions, absence of time constraints, anonymity, and fewer inhibiting social cues create an enhanced sense of control and a willingness to explore sensitive topics (Campbell et al.; East et al.; Fox et al., 2007; O'Connor & Madge, 2003).

Rationale

The suitability of the asynchronous BBFG modality for this medically fragile population and the benefits for the researcher are described here. For these participants, it is important for them to be able to respond in their own time over several days if unexpected personal or medical situations arise, to take more time to reflect on questions, and to “catch up” because some participants may easily fatigue, have limited attention spans, or learning disabilities. In the BBFG, questions are evenly paced over several days so that participants can log on and off as often as needed to complete the questions each day, or over several days. The BBFG format also provides the opportunity to balance easy to answer questions (just needing a check mark) with open-ended questions. Online research with this age group using a synchronous discussion has had disappointing response rates, confirming the benefits of the asynchronous format (Levine, Madsen, Wright, Barar, Santelli, & Bull, 2011)

Second, the BBFG provides potential for the researcher to interact with young adult participants via their preferred communication method (text or webcam), creating an inviting and engaging conversation. Customized responses, daily welcome and wrap up messages, mood and content setting visuals and video uploads can be used to stimulate participants' imagination and provide various modalities to engage their interest. Participants can upload pictures and images that depict their feelings in addition to their text and webcam responses (Barnes, 2012; iTracks, 2012; Van Patten, 2011).

Third, offline research activities such as projective exercises, ethnographic reflections and video projects can provide depth and dimension unavailable in live or online groups (Barnes, 2012). For example, in a BBFG, a question such as “What does the word ‘health’ mean to you?” can be expanded to: “Please find an image that best reflects what health means to you.” From the images posted, the moderator can stimulate conversation with and between participants to compare the meaning of their image with others. Ethnographic opportunities are opened up, with participants uploading videos and images they have of themselves, so that the researcher can “see” descriptions in addition to text based responses.

Fourth, for groups where fatigue and physical limitations are not a limitation, homework assignments such as recording journals, making physical or online collages, finding or creating pictures and videos all become possible data collection methods, enhancing traditional talk or text based formats (Barnes, 2012).

Finally, the BBFG formats can strengthen credibility of the research through (1) high response and retention rates, indicating that participants were interested and engaged over a long period of time (Franklin & Lowry, 2001; Im & Chee, 2006); (2) the immediate generation of transcripts directly from the participants' responses, including every word and textual descriptor (Kenny, 2005); and (3) a constant member checking, as participants post responses to both the researcher and other participants.

Development of the BBFG

Phase One: Question Guide Development

To develop questions for the bulletin board focus group, we utilized a content analysis of in-depth face-to-face interviews with young adults with pedLTC, with specialists in pedLTC and disabilities, and a review of relevant literature. Salient themes, issues requiring further investigation, and topics most amenable to an online format were chosen for question development.

Specific writing techniques that have proved successful and amenable in online formats (Barnes, 2012; iTracks, 2012; Van Patten, 2011) were used to create these questions. In face-to-face group or individual interviews, the moderator's question guide serves as a prompt for the discussion and allows adaptations for participants' responses and body language. In the online asynchronous discussion, the moderator guide is an actual script with a deliberate approach to structure and clarity (iTracks; Van Patten). Whereas the BBFG format requires pre-meditated structure, the moderator's role was to create a forum that appeared inviting, informal and engaging to the participants (Barnes; Van Patten). For example, the following introductory segment was worded to encourage participants to post divergent points of view in all writing styles, providing contextual information in addition to the text.

Different viewpoints and feedback on the topics are encouraged. And, if you see someone else talking about an experience you share or feel the same way about, add your thoughts too!

Don't worry about spelling, typos or grammar. I'm shur we'll be abul 2 figure out what ur saying. Feel free to use emoticons :-) coloured font, CAPITAL LETTERS, videos and pictures . . . be *cReative* !

Utilizing the BBFG required specific consideration of the ordering and flow of the questions. To avoid frustrating redundancy and repetition, responses to each question were anticipated with naturally emerging topics next to each other, which created cohesive groupings of questions and natural breaking points between the daily discussions (iTracks, 2012). Clear and complete online questions necessary to ensure that participants knew how to answer the questions being asked, and to enhance the quality and quantity of their responses. While questions posed on the BBFG were static, it was possible to improvise the wording of questions in response to previous participant comments, or add more context and content *ad-hoc*. Whereas structure and clarity are the backbone of the BBFG guide, personality and flow are essential for success (iTracks; Van Patten, 2011).

To ensure that the discussion was a rich and engaging dialogue among group participants, diverse question and response options were developed by the moderator (Barnes, 2012; Van Patten, 2011). A range of question types stemmed from viewing a video, reading a short vignette or a pictorial representation of the issues to build rapport, match varied interests, and open up possibilities for a range of answers (Teachman & Gibson, 2012). We anticipated that new comments and video responses would create a fresh and responsive virtual discussion among participants and moderator, and encouraged participants to provide more understanding and contextual information than text or webcam responses allowed, through questions that prompted them to upload images, videos or songs (Barnes, 2012). For example, in this BBFG participants were asked:

When you think about the future, what kinds of thoughts and feelings come to mind for you? If you can, please upload an image or picture that represents your feelings and thoughts about the future. Tell us what your picture or image means to you about the future.

Unlike a face-to-face focus group, where every participant does not answer every question, this BBFG required a response to each question before a participant could move on to the next. If participants preferred not to answer a question, they were prompted to type, “will come back” and then proceed with the next questions. If they were unsure of how to answer a question, they could review what others had said.

BBFG question development requires advance decision-making about the type of question required for participant responses. The following list describes the parameters for question and response types:

- Type of question: Open text, forced choice (yes, no, maybe, don’t know), rating scale and multiple choice style questions with the option of one or multiple answers
- Influenced or uninfluenced answers: Determines whether participants can see others’ responses before their own, or if must they write a response first before viewing the other participants’ responses
- Sequential or non-sequential: Determines whether questions must be answered in sequence, or if participants can skip around
- Time of launch of questions: When will each question or set of questions “go live”?
- Group/segmenting: Provides the opportunity to pose certain questions to specific respondents. Selected participants will see these questions, whereas others will not. Useful for segmenting questions between groups such as male/female, under/over certain ages, with disease/without disease. (iTracks, 2012)

Finally, it was important to collect some data regarding topics and themes that were not amenable to an online focus group discussion (for example, questions about with who and where they live, support required, current work, school or volunteer activities and accessibility). Instead of asking these questions in an online discussion, they were presented a day ahead of the “live” discussion, within the Profiles Section of the online forum. Participants could view each other’s responses here if they were interested.

Phase Two: Testing

Several iterative drafts of the moderator guide were developed through feedback from expert practitioners in pediatric palliative care, transition and neuromuscular diseases, a young adult with DMD, and academic supervisory committee members. Screen by screen review of the BBFG was tested and reviewed in cooperation with the host software company, ensuring compatibility of the requirements of participants for each screen with the software functionality. Examples of compatibility functionality testing included: video clips, forced and not forced answer screens, combined open and closed answer screens, optional response screens, and functionality and ease in uploading videos and images into the BBFG.

Managing Ethical Issues

Young adults who met eligibility criteria were contacted via email and invited to participate in the online focus group. We exchanged e-copy consents via email, with returned typed signatures serving as the participants' informed consent.

BBFG members were advised that although every precaution was taken to ensure confidentiality, it could not be guaranteed. Prior to entering the BBFG, participants read and signed a Terms of Service of Agreement with the host software company (iTracks, 2012). In addition to abiding by the company's rules of conduct, participants were advised to respect the privacy of their fellow participants by not repeating or sharing the information they read on the BBFG. Confidentiality of answers recorded via webcam was maintained through disabling the downloading and copying functions. As with any online activity, screen shots could not be prevented. Confidentiality of the data collected through the online focus group was protected through the comprehensive security measures of the "iTracks" software system, which includes the hardware, software, data security and storage.

Although no significant unwanted effects were expected from participating in the BBFG, each youth was provided with contact information (telephone, online, or in person) for access to a teen counsellor already known to them. Additionally, I closely monitored the nature, tone and content of comments posted and the reactions of other participants to the comments.

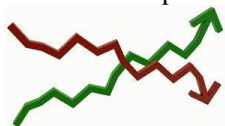
Implementation of the BBFG

If You Build It, Will They Come?

As described above, the BBFG discussion group guide required intense preparatory anticipation of participant responses. Every question, phrase, image, and uploaded video was scrutinized for appeal, functionality for a BBFG, and potential to expand the conversation. Table 1 provides an overview of topical themes for the BBFG, with a few examples of the questions posed for each topic.

Table 1. Bulletin Board Focus Group Topical Themes and Question Exemplars

Topics	Question Exemplars
Getting to know you	Lets watch this video called "Talk About Change" made by some young adults in Britain with life limiting conditions. The young adults in this video address lots of the topics we will be discussing. How are your experiences similar or different to what you have viewed? Tell us why.
Managing your medical condition	Thinking about your condition, In the next 2 years do you expect it to stay the same, improve, or decline? Please describe the expected changes.
Paving the Way	You are all pioneers and leaders because you are among the first to live with your condition into adulthood. If you were asked to come to a Teen Camp to help teens think about getting older with your condition, what would you tell them the most important things to keep in mind would be?



Hopes for the future	Being among the first with your condition to live into adulthood, what do you hope will be different for kids who are 10 years younger than you?
Transition Changes	Lets say that you are in a position to design a brand new health care program for people with a similar condition to yours. How would it work? Explain why you chose the aspects of the healthcare program that you did. Take a look at other people's program ideas and tell us what you think.
Getting what you need	We have been talking about the change in resources and support when you move from pediatric to adult care and the negotiating and advocacy involved to get what you need. Who is doing most of the negotiating or "fighting" for what you need? You? Parent? Someone else? Do you have anyone you can count on when things get really hard?
Relationships	On the video we saw the first day, one person said, "when they ask questions about me, they don't ask me, they ask the person I am with". A young woman with a complex condition told me that her wheelchair and equipment gets in the way of people seeing her as a person and knowing her for who she really is. Amy mentioned the other day that people don't expect you to be smart enough to go to university. How are your experiences similar or different? What do you think people would find the most surprising or interesting about you if they could see past your condition or being in a wheel chair? Post a picture or song, or whatever would represent what you wish people would really know about you instead of your wheelchair and/or condition.
Decision Making	What do you consider the toughest decision that you have ever had to make? Tell us about what made this the toughest decision? Who (or what) supported you in the process of making this decision? Or was it something you decided on your own?
Computers and Technology	"GAMING IS MY LIFE". How true is this about you? Feel free to elaborate on your answer in the textbox below.
Advanced Directives	Some of you will have already thought about advance directives (making sure other people know what you want done as your health declines) and some of you may not have. Answer these questions as best as you can. Do you have advance directives in place? If you do please tell us what your wishes are for your advanced directives

After vetting the BBFG and completing recruitment, the audit trail review revealed the moderator's anxious wait for the BBFG to go live. With all components of the project virtual and online, pre-launch uncertainty was high, wondering if participants would "show up" online, how the group would establish rapport, and if they would remain engaged for five days. The complexity of the participants' disabilities also created uncertainty about how much encouraging and "soft sell" was appropriate to ensure their engagement.

BBFG Live!

As expected, some participants were more conversational and provided more responses and contextual information than others. The two BBFGs produced an average of 220 participant posts over 5 days, yielding approximately 11 posts per participant per day.

Table 2. Bulletin Board Focus Group Participant Response Rates

User	Total # of Posts	Average # of Completed Questions	Available Questions	Average % Completion of Available Questions
BBFG 1	193	36	38	95
BBFG 2	244	37	38	97

Less conversational participants were encouraged to add more to the discussion through follow-up probing questions and an email alert that reminded them to go back to the discussion to answer further questions. The most conversational participants tended to be the most responsive to further probes. Knowing the possibility of learning disabilities in some participants, the moderator took care in determining the number of probing questions that should be asked, and whether to be chatty and conversational or be succinct, limiting the amount of content.

For those who had limited capacity to provide fulsome answers through text, the webcam provided another venue to participate. However, some of these participants told me that they did not think they could speak clearly enough to be understood. Others did not have an operational webcam, or else participated in the discussion using mobile device not equipped with webcam capabilities.

Keeping the conversation animated required an ongoing time commitment over the five day BBFG. No participants withdrew or stopped coming to the discussion, but on day 3 of 5, there was a noticeable dip in the amount of conversation and responses to questions. In addition to this mid-week lull in sticking with the daily commitment to the group, later discussion topics concerned relationships and intimacy, so participants might have experienced more difficulty forming responses. As moderator, the time commitment was very flexible; it proved easy to check in on the conversation and respond from a computer or mobile device. However, as in email correspondence, much more time was required to craft responses and phrase questions in text rather than in conversation. Especially with the sensitivity of topics about end of life, intimacy, and planning for the future with pedLTC, it was imperative to ensure that words on the screen were neither stark nor misinterpreted.

The moderator employed several strategies to maintain animated participation. Desired behaviour was rewarded by thanking participants publicly when they commented on each other's posts or gave detailed answers, and on the welcome and wrap-up screens. Using the webcam made it possible to speak conversationally and personally with the group, initiating further conversation. Also, participants were emailed an alert about follow-up questions, and when possible, referred to participant comments from previous days. Finally, as described above, a variety of question types, pictorial representations, vignettes and videos were used to keep participants engaged in the discussion (Van Patten, 2011).

The young adults with pedLTC who participated in this BBFG were positive about using this forum for research. For example: "I liked the variety of the topics and the way the responses were text or video. I liked the way the website is set up with profiles, and how you notified of new response so it's easy to answer." Another said, "Some of the topics really made me think and made me question some topics that I didn't think about before." These comments demonstrate that the BBFG was more than a method of collecting data. It created a networked community providing connectivity with peers to learn from each other, and share resources and common understandings. After the formal BBFG discussion had ended, participants continued to check back for more conversation. Their recommendations for change or improvement included, "I think it would be cool if these discussions lasted a little longer.

And also if they'd been a larger group, so that we could really get discussions going." Participants stated they would be very interested in participating again, and that they would highly recommend this BBFG to someone else.

Future Considerations

This BBFG demonstrates a new and novel research method to give voice to a medically fragile population with limited and divergent communication abilities. One of the greatest benefits of a BBFG is that data collection becomes an intervention. Questions and discussion amongst the group facilitates new ways of thinking about issues important to the participants. Travel time and costs for the researcher to visit participants individually, or for participants to travel to meet for a face-to-face interviews or focus groups would have been prohibitive. In the face-to-face interviews conducted to develop the BBFG, interviews were often delayed because of fatigue and changes in condition, and they fatigued easily when answering a series of questions. The online format provided the right amount of flexibility while maintaining a group discussion, cost effectiveness, and access to geographically disparate participants.

The limitations of this BBFG were similar to those identified in the literature: uneven participation by group members (Kralik et al., 2006), diminished group interaction dynamics (Kenny, 2005; Clapper & Massey, 1996), difficulty or lack of interest in following conversational "threads" (Moloney, Dietrich, & Strickland, 2003; Stewart & Williams, 2005), short responses because of limitations with typing and/or problems using webcam, and limited means for gathering contextual data (Kralik et al, 2006; Lovejoy, 2009) from those using text responses exclusively. Unlike a face-to-face discussion, when a BBFG participant does not respond to further questioning, it is not clear whether the participant ignored and/or did not know that further questions were posted, or if they had nothing more to say. Developing the online discussion and maintaining presence and fostering discussion on the discussion were time intensive.

Some challenges identified in the literature did not arise in this BBFG. For example, researchers have been cautioned that the use of non-standardized computer and internet jargon can be confusing (Im & Chee, 2006). We found no such instances in this BBFG; likely, the universal acceptance and understanding of abbreviations common in text messaging has made them less confusing. Participants used CAPITAL LETTERS, varied font colors, uploaded pictures, and emoticons to express both significant and subtle points. The proliferation of text communication through text messaging and social media sites such as FacebookTM has "normalized" text communication and appears to have nearly usurped face-to-face communication in adolescents and young adults. With the rapid advance of technology to provide sophisticated web-based communication for business and academia, earlier logistical issues that made it difficult for participants to log in, find the discussion or maintain connectivity throughout the BBFG (Im & Chee; Moloney et al., 2003) were no longer relevant. Finally, it proved unnecessary to eliminate any potential participants because of a lack of access to computers.

Table 3 summarizes the merits and detractors of the BBFG process for researchers and medically fragile populations. This paper describes one of the first attempts to employ an innovative research method to access an otherwise inaccessible population. The proliferation of social media, online discussions and text conversations makes this medium familiar and comfortable for young adults, and the diversity of physical limitations and communication modalities among the participants in this study demonstrated the inclusiveness and adaptability of an asynchronous BBFG forum. In addition to the technological capacity of the online format, the quality of data generated remains dependent on the skills of the researcher and moderator in building an engaging, personalized and coherent discussion over several days using varied

mediums. Continued refinement of these methods with more groups of hard to reach participants, more feedback about participants' experiences, and further understanding of the essence of the online discussion that can extend its purposes beyond a method to an intervention, will continue to add merit to BBFG methodology.

Table 3. Comparison of advantages and disadvantages of Bulletin Board Focus Group process for researchers and medically fragile populations

Research process	Advantages	Disadvantages
Participant selection		
Researcher	Increases accessibility and pool of participants Increases response rates ¹	Slow responses to email recruitment due to physical limitations or not being email users
Participant	Easy to decline through no response or email Reduces isolation and creates community ²	Inaccurate email address results in missing opportunity
Data Collection		
Researcher	Reduced time and costs Higher retention rates Enhanced theoretical saturation Control over methodological rigor of data collection Enhanced participation and easier discussion flow about sensitive topics ³	Unclear if theoretical saturation achieved when no response to further questions
Participants	Flexible timing to respond within their time zone, and work, family and leisure commitments Data collection is an intervention facilitating new ways of thinking More time to reflect and answer at their own pace Text format facilitates a concise discussion More interest in participating because the format is novel ⁴	Feel alone when unsure how to answer a question Time commitment required to log on every day
Data Analysis		
Researcher	Automatic and accurate verbatim transcripts Text and video analysis supported within BBFG Transcription costs, time and errors are eliminated More potential for theoretical saturation ⁵	Interface difficulties between BBFG transcript and NVivo software

Notes

The terminology to describe young adults with pediatric life threatening conditions (pedLTC) varies among authors. Some choose to use pediatric life limiting conditions (pedLLC) and others choose pediatric life threatening diseases (pedLTD). I chose to use pedLTC to distinguish this population from (1) pedLLC which has been used to describe youth with conditions that may be life limiting, but with expectations to live well into their 50's and

¹ Ahern, 2005; East et al., 2008; Fox et al., 2007; Im & Chee, 2006

² Beck, 2005; East et al., 2008; Fox et al., 2007

³ Cantrell & Lupinacci, 2007; Courtney & Craven, 2005; East et al., 2008; Fox et al., 2007; Im & Chee, 2006

⁴ Abbott, 2011; Ahern, 2005; Courtney & Craven, 2005; Fox et al., 2007; Moloney et al., 2003

⁵ Ahern, 2005; East et al., 2008; Fox et al., 2007

60's, and from (2) pedLTD which does not reflect that many of these young adults do not have a specific disease, but rather complex conditions with multi-system affect.

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