



Advantages and challenges of face-to-face and online methodologies: Researching adolescents experiences of nonterminal cancer in the family

Title	Advantages and challenges of face-to-face and online methodologies: Researching adolescents experiences of nonterminal cancer in the family
Author(s)	Rodriguez, Leonor
Publication Date	2020
Publisher	SAGE Publications
Repository DOI	10.4135/9781529734355

SAGE Research Methods Cases Medicine & Health Submission for Consideration

Case Title

Advantages and Challenges of Face-to-Face and Online Methodologies: Researching
Adolescents' Experiences of Non-terminal Cancer in the Family

Author Name

Leonor Rodriguez

Author Affiliation & Country of Affiliation

National University of Ireland Galway

Lead Author Email Address

leonor.rodriguez@nuigalway.ie

Discipline

Medicine [D23]

Sub-discipline

If you chose Medicine, Public Health, or Nursing as discipline, pick sub-discipline from the relevant list below. There are no sub-discipline options for Dentistry.

Cancer / Oncology [SD-MD-3]

[For Public Health: choose sub-discipline]

[For Nursing: choose sub-discipline]

Academic Level of intended readership

Advanced Undergraduate

Biography

Dr. **Leonor Rodríguez** is a postdoctoral researcher at the UNESCO Child and Family Research Centre, National University of Ireland (NUI) Galway. She has experience in health and clinical psychology working with families, children and adolescents who experience chronic illness and completed a Masters in Clinical and Health Psychology in her native Costa Rica. Leonor completed her PhD in the School of Psychology, NUI Galway; her PhD dissertation was titled, 'Understanding adolescent adjustment to maternal cancer: A study of personal experiences and psychological factors that promote adjustment'. As a postdoctoral researcher in the UNESCO Child and Family Research Centre, Leonor has carried out research and evaluation in the area of children and family support for the Irish Child and Family Agency as well as with Social Innovation Funds Ireland with an emphasis on programmes to promote mental health in children and adolescents. Leonor is interested in research methodologies, research ethics and the translation of research findings into policy and practice to promote social change.

Published Articles

Rodriguez L., Groarke A., Dolan P & MacNeela P. (2016) From cared to carers: Adolescent transition at a time of maternal cancer. *Children's Research Digest*, 3(2), 77-82.

Rodriguez L. (2018) Methodological challenges of sensitive topic research with adolescents. *Qualitative Research Journal*, 18 (1), 22-32. doi:10.1108/QRJ-D-17-00002

Rodriguez L., Groarke A and Dolan P. (2018) Adolescent adjustment to maternal cancer: An interpretative phenomenological analysis (IPA), *Qualitative Research Journal*, doi:10.1108/QRJ-D-17-00034

Rodriguez L., Groarke A and Dolan P. (2018) Individual predictors of adolescent adjustment to maternal cancer: The role of perceived stress, coping, social support, attachment and self-efficacy. *Cancer Reports*. doi:10.1002/cnr2.1.145

Rodriguez L. (2018) Selective Sharing: The impact of patterns of communication in adolescent experiencing maternal cancer. *Cancer Reports*.doi:10.1002/cnr2.1138

Rodriguez L. and Dolan P. (2019) It's your turn to step into their shoes' The role of empathy in adolescents experiencing maternal cancer. *Qualitative Research Journal*, 19(3), 213-224. doi: 10.1108/QRJ-D-18-00045

Rodriguez L. (2019) An exploration of resilience in adolescents facing maternal cancer. *Cancer Reports*. doi:10.1002/cnr2.1208

Abstract

This case study provides an overview of a research study with adolescents experiencing maternal cancer. It explores the methodological successes and limitations to promote a critical understanding of carrying out sensitive topic research with adolescents online and face to face. The study had a mixed methods design, including both quantitative and qualitative data collection methodologies. The suitability of these methods for the research objectives are described. Further reflection around the ethical and methodological implications of carrying

out participatory research with adolescents through challenging circumstances and experiences that may increase their vulnerability is provided.

Learning Outcomes

After studying this case study, students will be able to:

- Understand the methodological approaches of research with adolescents experiencing maternal cancer.
- Understand the ethical implications of sensitive online research with adolescents.
- Understand the advantages and challenges of sensitive topic research online.

Case Study

Project Overview and Context

This case study is based on my PhD thesis titled ‘Understanding adolescent adjustment to maternal cancer: a study of personal experiences and psychosocial factors that promote adjustment’ (Rodriguez, 2016). This study was carried out in Ireland and it involved participants from an international cohort including participants from Spain, United Kingdom, Costa Rica and the United States. Parental cancer is a stressful situation that can have a strong impact on adolescents’ lives (Giesbers et al., 2010; Helseth & Ulfsaet, 2003; Sieh et al., 2010; Su & Ryan-Wenger, 2007;); however, the state of the literature at the time showed conflicting findings: some studies suggested adolescents struggled but others suggested they adjusted well to parental cancer.

The objectives of this research were to

- explore the subjective experience of adolescents’ psychological adjustment to non-terminal maternal cancer with particular focus on perceived social support;

- explore mothers' perceptions of their adolescent's adjustment to maternal cancer;
- design and pilot an online intervention to enhance adolescent adjustment to maternal cancer;
- examine the role and relative impact of perceived stress, coping, perceived social support, maternal attachment and self-efficacy on adolescent adjustment (mood and well-being); and
- explore the mediating and moderating effects of social support in the relationship between perceived stress, coping and adjustment.

Section Summary

- This study set out to explore adolescents' experiences of maternal cancer, which can be considered sensitive topic research
- Careful consideration was needed to carry out sensitive topic research with this cohort.

Research Design

This research used a mixed methods design that included both qualitative and quantitative data collection. The qualitative data collection consisted of face-to-face telephone and online in-depth interviews with young people. The quantitative data collection was carried out online. Online research is a relatively new and growing field; and it can have a number of challenges, such as participant anonymity, confidentiality, informed consent and data protection (Battles, 2010). Online research is suitable for adolescents' research because adolescents have embraced and are proficient users of the internet and other digital technologies (Subrahmanyam, 2007).

Ethical principles and adolescent safety were a priority that impacted the research design and the overall methodological decision making of this online study. I designed a 'fit for purpose' online survey and intervention. I did not use readily available data online, but instead provided

participants with codes and personal links to access online so as to protect their identity and ensure that the information they provided was based on their own choice of how much or how little they shared. All participants under the age of 18 years provided consent to take part and so did their parents or guardians to ensure adults were aware of the involvement of adolescents in the research study.

Ethical and methodological risks were reduced to a minimum, therefore advantages of online research surpassed the risks. Advantages of this online study included the capacity to reach a larger sample and even an international sample of young people to increase the statistical significance of the findings. More adolescents engaged in the intervention and could have benefited from their involvement in it. Research costs were reduced as I did not have to travel to collect the data; instead, I spent my time in data analysis and dissemination to make an impact on how to support adolescents experiencing maternal cancer, informing practice and policy. Another advantage of this online study was providing a safe environment for adolescents to engage in ‘their own terms’: they could select the day and time that suited them to complete the intervention and they had access to the internet from their own home, which probably reduced the tendency towards ‘social desirable’ answers that often occurs when people are asked about sensitive topics face to face.

Participants

Participants in this study were 40 male and female adolescents (mean age = 16.78) whose mothers had been diagnosed with cancer within the previous two years. A subsample of these (N=14) and a group of 10 mothers with cancer (mean age = 48) completed “face-to-face” telephone or online semi-structured interviews to provide an in-depth understanding of maternal cancer, particularly to identify their unmet needs.

Methodological Considerations

This study had a mixed methods design, including a combination of qualitative and quantitative research methods. Mixed methods combines elements of qualitative and quantitative research approaches for the purpose of breadth, depth, understanding and corroboration of complex research questions (Muncey, 2009).

This research study was designed in three phases: qualitative, quantitative, and the intervention (pilot study).

Phase 1: Qualitative

This phase was qualitative as the main purpose was to carry out an in-depth and detailed exploration of the experiences and needs of adolescents experiencing maternal cancer, initially in the previous six months and later revised to the previous 24 months. This phase was intended to inform the following stages of the research and validate the knowledge from the literature on this topic. In the early stages of the literature review, I found that similar studies included children and adolescents without a specific focus on adolescence as a developmental stage and thus little was known about the experiences of this age group.

These qualitative interviews were analysed using a combination of qualitative research methodologies: meta-ethnography, thematic analysis and interpretative phenomenological analysis.

Meta-ethnography is a type of method for synthesising qualitative research across different studies and is focused on finding explanations for social and cultural events based on the perspectives of participants (Noblit & Hare, 1988). Meta-ethnographies have proven useful in

different fields and in specialized empirical research, as they provide a mechanism to understand how qualitative research contributes to the understanding of how, when and why an intervention may or may not be effective (Erwin et al., 2011; Kennedy & MacNeela, 2014).

Thematic analysis is a process to encode qualitative information by identifying, analysing and reporting patterns in the data that reveal core meanings in the text (Boyatzis, 1998; Buetow, 2010).

Interpretative phenomenological analysis (IPA) is a qualitative, experiential and psychological research approach which is committed to examine how people make sense of major life experiences in their 'own terms'. It examines in detail human lived experience (Smith, Flowers & Larkin, 2009).

Phase 2: Quantitative

This quantitative phase was intended to provide a baseline and postintervention measure of change over time for adolescents who engaged in Phase 3, the pilot of the online intervention. This phase was crucial as the definition of 'adjustment' was required to determine an adequate selection of scales that would provide an understanding of adjustment over time.

One of the initial challenges of this research was to define the concept of adjustment and therefore identify an appropriate means of measuring it. In this study, I used mood and well-being as determinants of adjustment. Previous research on this topic had an emphasis on negative outcomes and negative consequences as a result of maternal cancer; however, few studies had included measures that could capture positive aspects or gains for adolescents. Therefore, the literature on maternal cancer tended to emphasise negative aspects, not neutral

or positive aspects. Adolescents themselves in Phase 1 identified positive gains, and this informed my selection of measures for Phase 2.

I collected data for Phase 2 through Survey Monkey to facilitate online completion by participants. I then transferred the quantitative data to SPSS, a computer programme for statistical analysis, to identify how adolescent adjustment changed over time before and after they took part in the research. This analysis was descriptive; therefore, it was not possible to associate changes as caused by the intervention. More complex research methodologies such as randomised control trials (Kendal, 2003) need to be used to identify causality when evaluating the impact of interventions.

Phase 3: Online Intervention (Pilot Study)

This intervention was designed to support adolescents and promote their adjustment at the time of maternal cancer, informed by both the literature review and Phase 1 of the study. I designed Phase 3 to be a weekly session that would be sent to all research participants. This online intervention consisted of eight sessions approaching a variety of topics including cancer information, accessing support, social support, self-knowledge, emotional management, communication skills and family support.

I carried out a small-scale pilot study to validate the intervention before involving research participants to ensure it was appropriate. Further details on how the pilot study was validated are included in the Methods in Action section.

Section Summary

- I used mixed methods design that included both qualitative and quantitative approaches to collecting data online with adolescents facing maternal cancer.
- The study design included three phases: a qualitative phase, a quantitative phase, and a pilot study (intervention).

Research Practicalities

Recruitment Strategies

Recruiting adolescents for this study was challenging. One of the main reasons was establishing the correct timing. From the literature review, I noticed a pattern that very little to no knowledge was available about the first six months after a diagnosis of maternal cancer. Therefore, to me this timeframe suggested a gap in the literature worth exploring.

My initial public recruitment strategy included advertisements on local and national newspapers supported and approved by the university's media department. Additionally, I contacted local radio stations by email and social media to ask them to include information about this study in programmes that were relevant to the topic. I managed to coordinate some interviews to inform people about the study. This initial recruitment strategy provided some responses; however, all of them were beyond the six months in the inclusion criteria. Potential participants who replied to this call were up to five years after maternal cancer and therefore did not meet the inclusion criteria.

I then implemented a second recruitment strategy whereby I offered to deliver workshops in Cancer Support Centres across Ireland on the topic of how to speak to children and adolescents about cancer. This strategy provided me with a sense of 'giving back' to the community, patients and families. This was important to me from an ethical point of view, as I was not only

taking people's views to benefit me, but I was also giving them something in exchange. Again, a few people were recruited in this way, but some were outside the age range and the timeframe in the inclusion criteria.

At this stage, it became clear to me that the timeframe was wrong, so I decided to extend the timeframe to 24 months after a maternal cancer diagnosis. Adolescents themselves explained in Phase 1 that they found it difficult to speak about maternal cancer closer to the diagnosis and treatment. Others felt more comfortable exploring the topic several months after diagnosis or even after the treatment was completed.

Any significant changes in the methodology of the study need to be approved by the Research Ethics Committee; however, this depends on the specific committee you and the country are dealing with. It is important to communicate with your relevant committee to determine which changes require additional ethical approval before going into the field. In my case, I emailed the change as an 'amendment' to the Research Ethics Committee, as email was the committee's selected method of communication. It is important to understand the policies and procedures of local research ethics committees.

This study began as a local project in the Republic of Ireland. As recruitment proved to be difficult, I decided to open the research to international recruitment and include both Spanish- and English-speaking countries. I carried out online research to identify cancer support centres in different countries. I emailed them information about the study and requested their support for participants to engage in the research. I translated all materials and the intervention into Spanish. I identified validated scales in Spanish and English. There were small differences in both versions, which was a challenge for the analysis stages, as some scales were different sizes

and were also validated in different populations and groups. Thus, issues about validation emerged.

It is important to acknowledge these differences in scales used within the study, as such differences can have an impact on the findings. I used a statistical methodology to approach these validation issues. This method was standardization. This means raw scores were converted to Z scores and then converted to T scores, to allow comparison of scores from different tests measuring the same construct (Streiner & Norman, 2003).

International recruitment, therefore, was a good way to solve issues such as a restricted sample size; however, it posed another challenge at a later stage in the research, which I had not foreseen.

Providing age-appropriate information for adolescents to make informed decisions about their participation in research is crucial. Following best-practice guidelines of research participation (Lundy, 2018), I designed age-appropriate information sheets and consent forms and provided them to adolescents. Consent forms were written with simple language, excluding technical and scientific terminology, to ensure adolescents would have enough information to make an informed decision of whether or not they wanted to take part of the study. The form also had an attractive design, using figures and colours that would be appealing for the target age group.

Adolescents were given the opportunity to reflect on the information provided and then I contacted them again to determine their willingness to participate and respond to any queries or additional information they required. Additionally, I informed the adolescents that they could withdraw from the study at any time.

Gatekeepers

I provided local and international cancer support centres with an information sheet about the study via email. This information sheet explained the nature of the study and methodology, and included a request to act as gatekeepers to identify potential participants who had been engaged to their services. I carried out face-to-face visits to further discuss the study and the recruitment strategy with support centres; however, detailed communication with international cancer support centres happened by phone or online.

Once cancer support centres agreed to act as gatekeepers, they shared information through their contact lists and through social media or invited potential participants themselves. Each centre selected the methodology that they felt was most appropriate for them, and I adapted to their preference. Having this flexibility was beneficial, as cancer centres seemed happy to engage on their own terms and I had access to more centres, therefore opening more opportunities for participant recruitment.

Adolescents below the age of 18 years, for legal and protective reasons, require parental consent to engage in research. On occasions, practitioners and health staff from cancer support centres who agreed to be included in the study who had first-hand information of how the adolescents were coping suggested which families to contact, depending on the stage of the mother's treatment. This approach had the advantage that only families that were more likely to engage were contacted, without disturbing families that may have been more vulnerable or in crisis at the time. The disadvantage of this strategy is that a practitioner or a parent was essentially deciding for an adolescent whether or not the adolescent should be involved in the research, without allowing the adolescent to make his or her own decision. Research has found

that participation of children and adolescents in research is a balancing act between benefits of being involved and the child's need for protection (Kriz & Skivenes, 2017).

Some of the most successful strategies I used were ones targeted at adolescents themselves—for example, emails were sent through different universities to all students, student support, chaplaincies and student unions in universities, with the authorisation of the respective gatekeepers who had access to these data. The advantage of contacting adolescents directly is that they can make their own decision to be involved in the research or not, without the need for gatekeepers. The overall majority of my research sample was obtained as a result of this recruitment strategy.

Section Summary

- Participant recruitment in sensitive research such as maternal cancer can be challenging, so it is important to consider the appropriate timing to invite participants to engage—in this study, six months after diagnosis was too soon.
- Ethic committees may have to approve changes in research design, even if permission was initially granted. When carrying out international research, it may be necessary to include ethical considerations from other contexts.
- International research may mean the inclusion of data collection materials in different languages; thus, it is crucial to consider and control for any potential differences in the findings based on the differences in context and languages. Statistical measures such as standardisation can be useful.
- It is important to provide young people with enough age-appropriate information to make an informed decisions about their involvement in the research and their continuous engagement at the various stages of the research.

Method in Action: Advantages and Challenges

Phone, Online, or Face-to-Face Interviews

One of the strengths of this study was to provide a variety of ways in which adolescents could engage, including face-to-face, phone and online channels of data collection. This allowed adolescents to select the method with which they felt most comfortable, according to their personality and their preferred way of coping with a sensitive topic such as maternal cancer. Having a variety of options also contributed to recruitment, as adolescents were given a choice and it was me, the researcher, who adapted to their preference. Previous studies have suggested that online methods of data collection may increase participants' willingness to communicate about sensitive issues (Krumpal, 2013; Tournageau & Smith, 1996).

Another advantage of this study was the possibility of engaging at different phases of the study. Some adolescents did not want to engage in Phase 1 of the study, as this required them to speak about their experience, which they found challenging; however, some seemed to feel comfortable completing anonymous surveys online, as their identity was not revealed. Adolescents made these decisions themselves and informed me by email or by phone about their choice. I believe that having options and allowing adolescents to engage in ways they felt comfortable with contributed to research participation and retention.

With regard to participant identity, it is important to consider that the Internet is a public domain and risk to anonymity and confidentiality may exist online. Therefore every effort needs to be put in place to ensure sensitive and/or identifying data are not publicly released (Kraut et al., 2004). In this case, I provided participants with unique personal links to the online survey and the online intervention. Data were collected and reported as anonymous group data

only. Personal information was stored in a password-encrypted file in a password-encrypted computer that only I had access to.

Online Intervention

I designed an intervention for adolescents experiencing maternal cancer. The components of this intervention were informed by a vast review of the literature available on interventions for children and families experiencing illness and cancer. I also included the findings of Phase 1 of this research whereby adolescents themselves shared their experiences, identified their needs and provided ideas of how they could have been supported at the time of maternal cancer.

The intervention consisted of eight one-hour sessions available online on the Survey Monkey Platform. Each session had a specific objective and corresponding activities that adolescents completed online.

The topics I included in the intervention were:

1. Information about cancer, how to ask for help and how to provide support for the ill parent and other family members.
2. Ways to identify social support and access support.
3. Self-knowledge, including how to identify their own strengths, talents and coping skills.
4. Emotion management, self- control, relaxation and meditation techniques.
5. Assertive communication and listening skills.
6. Open and honest communication about cancer.
7. Reciprocal support, including asking for and receiving help.

8. Understanding the personal experience of maternal cancer and their experience of participation in the intervention—participants completed a short online survey to provide written feedback of the intervention, including what they liked and suggested improvements.

I selected an online intervention because it had several benefits that I describe in detail here. I also took into consideration the potential risks that online interventions could have and how I approached these issues. Advantages of online interventions include:

- Adolescents are used to technology and the majority have regular presence online therefore this would increase their interest and engagement in the programme.
- Adolescents usually depend on other people to travel to venues and activities; therefore, the online programme would facilitate access at any day and any time that suited them.
- Adolescents who did not feel comfortable talking about maternal cancer face-to-face might be attracted to an online option where they would not have to speak publicly about the issue but could still approach it.
- Geographical barriers were also surpassed with online interventions as adolescents from various contexts and locations could have access to the programme, which has been identified by previous research as one of the benefits of online research (East et al., 2008).

Online interventions also have limitations, which were challenging for me to foresee and to avoid. These included costs, safety, and retention.

Costs

Having an attractive and interactive website can have a cost. In this case, I used Survey Monkey to design the intervention. However, to have access to this platform, I had to pay an annual

subscription fee. I encourage researchers to carry out a thorough research to compare costs, considering the budget available and the suitability of different programmes and platforms to fulfil the objectives of their study. Building an attractive website for adolescents requires knowledge and skill in this field. Therefore, the costs of design and maintaining the website need to be considered in the overall process and initial budget.

Safety

Guaranteeing safety online was another significant aspect to consider. I therefore decided to give only individual access to all participants to the sessions. Although this helped to guarantee safety, it limited the support participants could have provided to each other as they were experiencing similar circumstances. In Phase I, some adolescents expressed a desire to talk and share with others, whereas others expressed that they did not want to. These individual preferences need to be considered to increase the effectiveness of interventions.

Caring and guaranteeing the safety of participants is a crucial aspect to consider when designing an online intervention. I carefully considered situations such as cyberbullying or any kind of online abuse that adolescents could be exposed to so as to avoid them completely. Online groups require constant monitoring and/or moderating, and this was not feasible for me. Additionally, adolescents experiencing maternal cancer could have been experiencing difficulties and challenges themselves and may have required additional support. Even though I am a trained professional with experience in debriefing and crisis intervention, the online environment limited the amount of support I could provide to participants. Therefore, I decided to exclude terminal cancer from the study. There may have been strong reasons to consider that adolescents experiencing terminal maternal cancer instead were the ones in most need of

support; however, I was conscious of the limited support I could provide online in comparison to the type of support I could provide face to face.

As part of the ethics application, I was expected to design protocols to specify how I would cope with participant distress that might arise during data collection. Due to the international nature of the sample I, tailored these protocols to the country of origin of participants. I selected these support services online and I also asked for the advice of cancer centres themselves to ensure the supports I had identified were relevant in their context. The protocols I created were intended to guide adolescents to free face-to-face supports in their local areas if necessary. Previous research online has suggested that human contact online can be less, providing empathetic support for participants is more limited than in person as no physical or tangible support can be provided (Rodriguez, 2018).

Retention

Another challenge of online interventions was retention. This intervention was subject to a small-scale pilot study with adolescents prior to Phase 3, a large-scale pilot study with research participants. Evidently, the intervention must be good to attract the long-term interest of adolescents; however, opportunities to build rapport between the researcher and the participants were limited. Previous research has identified rapport and human relationships as crucial for retention in research studies; however, these opportunities can be limited in online interventions that rely on self-completion.

Participation of children and adolescents is also enabled by building a relationship of trust (Cossar, Brandon & Jordan, 2014; Kennan, Brady & Forkan, 2019). To overcome this limitation, I created online videos in which I explained the programme instead of using impersonalised written text and descriptions. This allowed adolescents to meet me. If this

intervention were to be carried out again, more interaction could be encouraged. For example, instead of providing written feedback on the intervention, I might give adolescents tools to provide video feedback. This would have also provided an opportunity to ensure adolescents were coping well while they were involved in the programme.

If adolescent had queries or required any kind of support from me, the intervention had clear contact information and the option to contact me by video call or telephone calls; however, nobody availed of it, probably because I did not direct them to this option. I waited for them to make the decision around frequency and media of contact with me.

Providing Feedback

Providing feedback is a crucial pillar of participatory research with children and adolescents (Lundy, 2007; 2018). This study did not fully comply with this due to several issues that are worth reflecting on.

Time Between Publications and Data Collection

Time between data collection, analysis, write-up and further dissemination was an average of two years. This meant that the contact with participants was not sustained and some participants had changed their contact details over that period. An important lesson from this experience was the need to clearly explain to participants in consent forms and information sheets not only how information will be disseminated but also the expected time that would pass between data collection and dissemination. Participants need to have the option to opt in and opt out of being contacted by researchers over time, as their interests and/or circumstances might have changed.

One of the issues to consider when carrying out research with adolescents experiencing maternal cancer is the reality of maternal loss. Even though all parents had survived at the end

of the data collection period, there may have been some cases where this had changed and adolescents may not want to be involved in the research process anymore or have any kind of contact from the researchers.

Funding for Dissemination

One of the possible options for dissemination in online research is to continue to provide access to participants on the online platform where the research was carried out and use this to upload any dissemination material resulting from the research. In this way, engaging would be a choice that participants make to access outputs if they wish to do so on their own terms.

The challenge of this option is the cost of keeping the platform online over time, a cost which probably needs to be included in the research budget. In this case, funding was provided from a PhD scholarship and thus was only available over a determined period. Adolescents should be given clear guidelines as to where and how they can access outputs in the future if they wish to do so.

Appropriate Methods for Dissemination

Individual participants were sent published academic articles based on the research findings by email; however, these outputs were not age-friendly and I received very little feedback from participants from this exercise. I should have given more and better consideration to age-appropriate methodologies to disseminate research outputs. For examples, I could have directed participants to an online blog hosted on a readily available, free platform. However, I considered these options only after the research was completed and I lost contact with participants. Providing feedback to children and adolescents should be part of a research continuum, a part as crucial as any other of the full research process.

Pilot Study

The pilot study also presented some challenges. The online intervention was validated in a small-scale study with male and female adolescents in the target age range of potential research participants before the research participants completed the intervention themselves. Ethical considerations around the pilot study were important. To avoid unnecessary distress, the small-scale pilot study did not include adolescents who were experiencing maternal cancer in the validation process of the intervention, previous to the large-scale pilot study carried out to validate the intervention. The justification for this was to avoid any upset or discomfort in adolescents who had experienced maternal cancer, as they were asked to judge the content, image and activities included in the intervention but they were not going to be fully supported psychologically in the process. All adolescents included in the pilot study were provided with the research distress protocol in case their involvement in the pilot phase generated any kind of difficulty.

Summary Section

- One of the positive aspect of this research was the inclusion of different ways for adolescents to engage in the research, showing respect towards adolescent decision-making and also contributed to participant retention.
- Guaranteeing the safety of participants is one of the utmost ethical principles of research; thus, distress protocols need to be in place in case participants are distressed are any stage of the research.
- Online interventions with adolescents can have several benefits (e.g., adolescent engagement and proficiency online, access at any day and time, breakdown of geographical barriers) as well as limitations that need to addressed in the research

design (e.g., participant protection, potential costs of websites, limited support that can be provided for participants online in case of distress, participant retention).

Practical Lessons Learnt

This case study provides evidence of the benefits and potential limitations of carrying out online research on sensitive topics with adolescents. Research online has both advantages and limitations that need to be addressed to justify the use of this method and to ensure that it is ethical and high-quality research.

Information online can be publically available and data breaches can also happen, which may release participant identifiable information. Security measures need to be in place, for example using participant codes instead of names, providing unique and individual links for participants, and avoiding groups and forums if constant monitoring is not possible. All information in hard or soft copy should be kept safely locked or in password-encrypted files and computers. Participant safety, particularly with participants under the age of 18, is a major concern for gatekeepers. Clear guidelines on how participants will be protected in the study and distress protocols need to be in place to increase the confidence of gatekeepers to commit to participant identification and selection.

Capturing the voices and opinions of adolescents meaningfully is an important part of the research design. Adolescents should be allowed to make informed decisions about their participation in the study but also be given the opportunity to refuse participation at any stage of the research process. This was achieved in this study by allowing adolescents to engage in all phases of the study or just some of the phases. This was a way of respecting their decisions and avoided excluding them from the study. Additionally, consent forms were tailored to

include simple and non-technical language, which ensured that adolescents were informed and understood the information they were provided with to make decisions. The large-scale pilot study also had a small-scale pilot study in which adolescents were asked to judge the adequacy of the format and content of the research for their age group.

Section Summary

- Online research with adolescents is feasible as long as care and protection measures to ensure their safety online are in place.
- Gatekeepers are essential for research recruitment; however, they should make a conscious balance between the benefits of participation versus the possible risks or harm for adolescents engaging in research.
- All adolescents should be given an opportunity to make their own informed decision about engaging in research or not. Age appropriate information should be provided to them to ensure their decisions are informed.

Conclusion

This study found that adjustment needs to be understood as a process rather than as an outcome since maternal cancer is a succession of phases that can have different demands on adolescents. Having information about cancer and normalizing emotions were the main needs reported by adolescents. Adjustment needs to be approached in a holistic manner to understand the influence of environmental factors in adolescents' experiences, particularly family structure. Individual differences in perceived stress, coping skills, social support, attachment and self-efficacy can have an impact on adolescents' adjustment experiences, and adolescents with higher levels of social support experience more positive outcomes (Rodriguez, 2016). Adolescent experiences are influenced by developmental factors (i.e., age, gender), which

should be taken into consideration when examining the needs of adolescents who experience maternal cancer. This study found that adolescents could identify positive experiences from what was also a very difficult experience for them.

Online research with adolescents experiencing maternal cancer can be described as an appropriate research design, not without its challenges. Recruiting adolescents experiencing maternal cancer can be challenging, as cancer can be a sensitive topic that is difficult for people to talk about. Therefore, a variety of data collection methods may give adolescents more choices and a sense of power to make their own decisions, which could motivate them to engage in a research study.

The timing of this study was wrong. Resources and effort went into recruiting adolescents six months after diagnosis; however, the participants who eventually took part in the study were within 24 months of their mothers diagnosis. Therefore, timing for recruitment needs to be carefully thought through so no resources are invested in unsuccessful recruitment.

Section Summary

- Recruiting participants for sensitive topic research can be a challenge, so careful consideration should be given to recruitment strategies to ensure sample sizes required for the objectives and research designs are achieved.
- The timing of data collection is an important consideration. Adolescents may need a longer period to cope with the situation they are experiencing and to speak about it.

Classroom Discussion Questions

1. What are the advantages and limitations of mixed methods research? If you were to consider using mixed methods for your own research, how would you go about addressing these limitations?
2. What are the risks of online research with children and young people? How can such risks be mitigated?
3. Is sensitive research online an ethical practice? Explain your answer.
4. Including the voice of children and young people is good practice. This study provided some suggestions of how to capture young people's views and support their decision making (e.g. age- appropriate information). As a researcher, can you suggest how you can ensure the voices of children and young people can be meaningfully captured in all stages of a research study?

Multiple Choice Questions

1. What are advantages of online research over face-to-face research?

- a) Researchers can provide equal amounts of support for participants in distress online as if they were face to face.
- b) *Online surveys can reduce research costs and reach a geographically disperse sample- Correct.*
- c) Online surveys have less risks than face-to-face surveys for participants.

2. What are ethical requirements of research with children and adolescents?

- a) *Parental consent, anonymity, confidentiality and informed decision making. Correct.*
- b) Parental consent and children and adolescents' will to use the Internet.
- c) Access to the internet, computer skills and gifts for children and adolescents.

How can researchers protect participants involved in online research?

- a) *Avoid the distribution of personal information online and ensure distress protocols are in place.*
- b) Include only adults in the research as they are the only ones who can provide informed consent to be included in the research.
- c) Facilitate groups and discussion boards where participants can support each other with minimal monitoring from the researcher.

Declaration of Conflicting Interest

The Author declares that there is no conflict of interest.

Further Reading

Battles H. (2010) Exploring ethical and methodological issues in internet-based research with adolescents. *International Journal of Qualitative Methods*, 9(1), 27-39.

Braun V. & Clarke V., 2006. Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77-101. doi:10.1191/14780-88706qp063oa.

Department of Children and Youth Affairs (DCYA) (2015) National Strategy for Children's and Young People's Participation in Decision Making, 2015–2020. Dublin: Stationery Office.

Hauskov, A., Roested C., Haavet O., Smith-Siverten T. & Makela M. (2019) Somatic symptoms in children who have a parent with cancer: a systematic review. *Child: Care, Health and Development*, 45 (2), 147-158. doi:10.1111/cch.12647

Hill M. (2005). Ethical considerations in researching children's experiences. In S. Greene & D. Hogan. *Researching children's experience*. London: SAGE Publications Ltd.

Kennan, D. and Dolan, P. (2017) Justifying children and young people's involvement in social research: Assessing harm and benefit, *Irish Journal of Sociology*. doi: 10.1177/0791603517711860.

Kennan D., Brady B., & Forkan C. (2018) Supporting children's participation in decision making: A systematic literature review exploring the effectiveness of participatory processes. *British Journal of Social Work*, 48, 1985-2002. doi:10.1093/bjsw/bcx142

Noblit G. and Hare, R. (1988) *Meta-Ethnography. Synthesizing qualitative studies*. United Kingdom: SAGE Publications.

Subrahmanyam K. (2007) Adolescent online communication: old issues, new intensities. *Journal of Psychosocial Research on Cyberspace Cyberpsychology*, 1 (1).

References

Battles H. (2010) Exploring ethical and methodological issues in internet-based research with adolescents. *International Journal of Qualitative Methods*, 9(1), 27-39.

Boyatzis R. (1998). *Transforming Qualitative Information. Thematic Analysis and Code Development*, United States: Sage Publications.

Buetow S. (2010). Thematic analysis and its reconceptualization as 'saliency analysis'. *Journal of Health Services Research & Policy*, 15 (2), 123-125. doi: 10.1258/jhsrp.2009.009081.

Cossar J., Brandon M. & Jordan P. (2014) 'You've got to trust her, and she's got to trust you': children's views on participation in the child protection system. *Child & Family Social Work*, 21(1), 103-112. doi:10.1111/cfs.12115

East, L., Jackson D., O'Brien L. & Peters K. (2008). The benefits of computer-mediated communication in nursing research. *Contemporary Nurse*, 30(1), 83-88.

Erwin E., Brotherson M. & Summers J. (2011). Understanding qualitative metasynthesis. *Journal of Early Intervention*, 33(3), 186-200. doi:10.1177/1053815111425493.

Giesbers J., Verdonck-de Leeuw, van Zuuren F.J., Kleverlaan N. & van der Linden M.H. (2010). Coping with parental cancer: web-based peer support in children. *Psycho-Oncology*, 19, 887-892. doi:10.1002-/pon.1636

Helseth S. & Ulfsaet N. (2003). Having a parent with cancer. Coping and quality of life of children during serious illness in the family. *Cancer Nursing*, 26, 355-362. pmid:14710796.

Kendal J. (2003) Designing a research project: randomised control trials and their principles. *Emergency Medical Journal*, 20 (2), 164-168.

Kennan D., Brady B. & Forkan C. (2019) Space, voice and influence: The Lundy Model of Participation (2007) in child welfare. *Practice. Social Work in Action*, 31(3), 205-218. doi:10.1080/09503153.2018.1483494

Kennedy L.A. & MacNeela, P. (2014). Adolescent acculturation experiences: A meta-ethnography of qualitative research. *International Journal of Intercultural Relations*, 40, 126-140. doi:10.1016/j.ijintrel.2013.11.003.

Kraut R., Olson J., Banaji M., Bruckman A., Cohen J. & Couper M. (2004). *Psychological Research Online*. American Psychologist, 59(2), 105-117.

Kriz K. & Skiveness M. (2017) Child welfare workers' perception of children's participation: a comparative study of England, Norway and the USA (California). *Child & Family Social Work*, 22, 11-22. doi:10.1111/cfs.12224

Krumpal, I. (2013) Determinants of social desirability bias in sensitive surveys: A literature review. *Qual Quant*, 47(4), 2025-2047.

Lundy L. (2007) 'Voice' is not enough: conceptualising Article 12 of the United Nations Convention of the Rights of the Child. *British Educational Research Journal*, 33(6), 927-942. doi:10.1080/01411920701657033

Lundy L. (2018) In defence of tokenism? Implementing children's right to participate in collective decision-making. *Childhood*, 25(3), 340-354. doi:10.1177/0907568218777292

Muncey T. (2009). An overview of mixed methods research. *Journal of Research in Nursing*, 14(2), 187-188.

Noblit G. and Hare, R. (1988) *Meta-Ethnography. Synthesizing qualitative studies*. United Kingdom: SAGE Publications.

Rodriguez L. (2016) *Understanding adolescent adjustment to maternal cancer: a study of personal experiences and psychosocial factors that promote adjustment* (Unpublished doctoral dissertation). National University of Ireland, Galway.

Rodriguez L. (2018) Methodological challenges of sensitive topic research with adolescents. *Qualitative Research Journal*, 18 (1), 22-32. doi:10.1108/QRJ-D-17-00002

Sieh D., Meijer A., Oort F., Visser-Meily J. & Van der Leij D. (2010). Problem behaviour in children of chronically ill parents: a metanalysis. *Clinical Child and Family Psychological Review*, 13, 384- 397. doi: 10.1007/s10567-010-0074-z.

Smith J., Flowers P. & Larkin M. (2009) *Interpretative phenomenological analysis. Theory, method and research*. London: SAGE Publications Ltd.

Streiner D. & Norman G. (2003) *Health measurement scales. A practical guide to their development and use*. United States: Oxford University Press.

Subrahmanyam K. (2007) Adolescent online communication: old issues, new intensities. *Journal of Psychosocial Research on Cyberspace Cyberpsychology*, 1 (1).

Su Y. & Ryan-Wenger N. (2007). Children's adjustment to parental cancer: a theoretical model development. *Cancer Nursing*, 3, 362-381. doi: 10.1097/01.NCC.0000290817.37442.e6.

Tourneau, R. & Smith T. (1996). Asking sensitive questions. The impact of data collection mode, question format and question context. *Public Opinion Quarterly*, 60(2), 275-304.