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Ethical Considerations for Student-Based Reminiscence Projects

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In this paper we address ethical issues instructors should consider when designing reminiscence-based projects for student interviewers and older participants. We describe three basic ethical principles developed within the context of research with human subjects: respect for persons, beneficence, and justice (Belmont Report, 1979). We then discuss how these principles can be adapted for student-based reminiscence projects. Specific issues addressed include informed consent, confidentiality, and fairness in selecting participants.

Intergenerational reminiscence programs bring younger and older people together to exchange stories about their lives. This activity is often conducted within an educational setting, linking older storytellers with student interviewers at all levels of education from grade school through college (Gibson, 2011). Students taking part in these programs gain an opportunity to hear about a lifetime of successes, failures, and challenges experienced by older adults—and to imagine what they would do if placed in similar situations.

Student-based reminiscence projects can take many forms and have widely different goals. For example, in a more family-based setting, students working with older relatives have the chance to get to know them in new ways through descriptions of meaningful experiences earlier in their lives (e.g., life as a child and adolescent in an earlier era, courtship of their spouse, parenting, difficult life events, career experiences, leadership roles). In other, more community-based projects students work with older people they may have never met before and have a chance to interact with an older participant who may potentially hold a very different worldview. In community-based reminiscence projects, products resulting from reminiscence interviews (e.g., written transcripts, audio or video recordings) are often presented and/or stored in a public

place (e.g., local library, online) as part of a permanent record of the lives of members of that community (Pierce, 2017).

The benefits of intergenerational reminiscence projects for both student interviewers and older storytellers are significant and have been demonstrated through research (e.g., increased appreciation for older adults among student interviewers, Chung, 2009; enhanced quality of life in persons with mild to moderate dementia, George, 2011). At the same time, work of this type is not without risk. For example, older storytellers must trust younger interviewers to keep confidential those pieces of information they wish to remain private. In addition, in some people, recalling memories of lost loved ones can elicit strong feelings of sadness (e.g., Eisma, Schut, Stroebe, Voerman, van den Bout, Stroebe, & Boelen, 2015). We believe it is important for persons organizing intergenerational reminiscence projects and student interviewers to be aware of their ethical obligations towards the older storytellers with whom they work—specifically, by maximizing the benefits of participation and minimizing the risk of negative outcomes.

The purpose of this article is to provide instructors in the planning stage of a student-based reminiscence project with a suggested framework for managing the ethical issues they are most likely to encounter. Specifically, our discussion is based on the principles of ethical conduct outlined in the Belmont Report (1979), which summarized the ethical obligations of scientists when conducting research with human subjects. Although the classroom-based reminiscence programs we're talking about do not fall under the umbrella of scientific research, we believe the ethical principles and recommended practices contained in the Belmont Report provide an excellent starting point in guiding the behavior of students participating in reminiscence projects. By engaging them in a discussion of these recommended practices,

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instructors can take advantage of a “teachable moment” to introduce 1) basic principles of ethical thinking, and 2) techniques for becoming effective interviewers.

The Belmont Report and Student-Based Reminiscence Projects

The Belmont Report summarizes ethical issues pertaining to work with human subjects in terms of three major principles: respect for persons, beneficence, and justice. After presenting a brief discussion of each principle, we provide examples of how it can be applied to work with older adults in student-based reminiscence projects. It is important to note that there is often overlap among these principles and that they occasionally come into conflict with each other. The nature of human ethics is contextual and constantly evolving, such that if the appropriate course of action were always easy and obvious, there would be no need for the field of human ethics to exist. Although many of the ethical issues identified in this paper apply to work by students with family members (in which the products of reminiscence sessions will be held privately within the family), a number of important issues are relevant only for community-oriented projects in which the products of reminiscence sessions (e.g., written transcripts, audio or video recordings) will be made available in some public fashion (e.g., held in a public library, posted online).

Respect for persons

The principle of respect for persons recognizes the right of people to make decisions for themselves and to exert control over events and circumstances that affect them. An important term used to represent this idea is *autonomy*. Our responsibilities regarding respect for persons have been met when the people we recruit as participants have all the information they need to act independently to represent their own interests. For persons whose ability to act autonomously has been compromised (perhaps through a decline in cognitive function), this responsibility is satisfied when their best interests are represented by people designated to make decisions on their behalf (e.g., a family member or legal guardian).

The principle of respect for persons is evident when older adults are asked to provide their *informed consent* to participate in the project. While most instruction-based reminiscence projects are not required to obtain informed consent¹, we believe that doing so makes it clear that the interviewer respects the right of participants to retain

control over both their role in the project and any final products. The Belmont Report emphasizes three elements of informed consent. First, participants must be given sufficient *information* to know 1) what exactly they will be asked to do, 2) the risks and benefits of participating, and 3) how the reminiscences they provide will be used. If the project team intends to make recordings of the participant’s reminiscences publically available (e.g., written transcripts, audio or video recordings), this should be stated clearly in the consent document, accompanied by a statement that the participant will have an opportunity to review and approve any materials that will be made publically available. Second, this information must be presented using language they can understand. This feature of *comprehension* takes into account both the level of language used (e.g., vocabulary, sentence complexity) and the language itself (i.e., providing information in languages other than English, when appropriate). In situations where a participant maintains a normal ability to comprehend the language used to obtain informed consent but the person’s ability to read a consent document and provide a signature are compromised, a project member can read the consent information to them and document verbal provision of consent (preferably in the presence of a witness). The third element of informed consent is *voluntariness*, where participants are explicitly told that 1) no one is required to participate in the project if they don’t want to, 2) they can decline to answer any question with which they are uncomfortable, and 3) they can end their participation at any point without negative consequences. We provide a sample consent form in Appendix A.² In short, no one should feel pressured or coerced into participating in any part of the project. On a practical note, instructors organizing reminiscence projects should make contingency plans for working with students whose interview participant withdraws early from the project.

Beneficence

The ethical principle of beneficence (*bene-* meaning “good” and *-ficence* referring to a “deed or action”) encompasses two complimentary obligations on the part of student interviewers. These consist of providing benefits to participants and protecting them from harm.

Maximizing project benefits. There are many things student interviewers can do to make the project as positive an experience for participants as possible. For example, they can make it clear that they are enjoying the company of the older adult and that they appreciate the time the

¹ This is so because instruction-based reminiscence projects typically do not meet the federal definition of research, which is “A *systematic* investigation, including research development, testing and evaluation, *designed* to develop or contribute to generalizable knowledge.” (Code of Federal Regulations: 45 CFR 46.102)

² The sample consent form is for a hypothetical project in which high school students are 1) making video recording of reminiscences of older

adults in their community, 2) creating edited videos of interviews, and 3) providing these videos to the local library so they can be viewed by members of the community. Because instruction-based reminiscence projects can take many forms, instructors adopting a different program model will need to adapt their consent form accordingly.

participant is giving them. In addition, students can express their interest in participants' life stories by devoting their full attention to them during interviews and by asking thoughtful follow-up questions.

After interviews have been completed, students should take as much time as needed to produce high quality reminiscence products³ that participants will be pleased and proud to share with family members and friends. Producing high quality products is a fundamental part of providing maximal benefit to older storytellers, and it reflects the care and respect we have for the personal information the older storyteller has entrusted to our project. An important part of this process is providing participants with the opportunity to review the product based on their reminiscences (e.g., a written transcript, audio recordings, edited video of reminiscence sessions). This is particularly important because learning that personal information has been used in unexpected and undesired ways can be a highly negative experience for the person who provided it.⁴ Examples of products requiring significant investments in time on the part of students include transcripts of recorded interviews, edited videos (e.g., Yancura, 2013), and PowerPoint presentations containing scanned photographs and recorded reminiscences (e.g., Pierce, 2013).

It is important to note that on occasion a storyteller may make statements that reflect significant cultural, political, or generational differences that a student interviewer may find objectionable (e.g., a racially insensitive remark). This creates a conflict between the need for storytellers to feel validated in their beliefs and possible discomfort on the part of student interviewers. Instructors should discuss ahead of time possible strategies students might use to avoid this type of situation or how to address it if it occurs (e.g., changing the topic of conversation).

Minimizing costs. While the first component of beneficence consists of maximizing benefits to participants, the second is arguably more important: protecting them from harm. For the most part, reminiscence is an affirming and normal part of everyday life; however, there are circumstances where revealing personal information can have negative consequences for participants and possibly for family members, friends, colleagues, and others. Student interviewers can reduce the risk of these negative effects by maintaining *confidentiality* regarding material participants do not want

known outside the interview session. Effective communication is a vital component of this process. Many times, without being prompted, an older storyteller will indicate which parts of an interview they are comfortable making publicly available (e.g., as part of class discussions or archived collections of reminiscences). At this point, the student's obligation is to acknowledge and abide by the storyteller's wishes. At other times, students will need to be proactive and directly ask the storyteller for guidance regarding what information they are comfortable with the interviewer sharing. Additionally, instructors should repeatedly emphasize to students the importance of refraining from informal discussions or gossip about information that was provided in confidence and not meant to be shared (or accidentally overheard) in any public or private context.

An additional note regarding limits of confidentiality is warranted. In rare circumstances, a storyteller may become visibly distressed or agitated, or provide information regarding topics that students and their faculty supervisors are not qualified to address (e.g., expressing a desire to harm him or herself, reporting that they are being abused or mistreated). Although a thorough discussion of such scenarios is beyond the scope of this paper, it is imperative that a plan of communication be discussed in advance to assure that qualified professionals with expertise in this area will be notified in a timely manner so they can provide follow-up assessment or interventions to address the concerns raised.

As an example of a situation where a student could prevent a negative effect of participation by an older storyteller, suppose the older participant revealed a piece of personal history that the student interviewer believes could be potentially damaging to them in some way; perhaps the storyteller describes an incident that presents a family member in a negative light. If this story becomes archived at the local public library or online, the family member may become upset by having the story displayed in this public fashion. There is a high likelihood that the person providing the reminiscence will experience a rift in their relationship with the person described in the story and possibly with other members of their family or community. Clearly, for this participant, the potential costs from revealing this information may outweigh any benefits they may receive.

Acknowledging that it is impossible to anticipate every consequence of making life stories publically

³ By "high quality" we do not mean "professional-level quality" but a good faith attempt to produce products that students would feel comfortable providing to their own family members. Yancura's (2013) article "How to Make Reminiscence Movies: A Project-Based Gerontology Course" provides an excellent description of what students and instructors can reasonably hope to attain in terms of the technical quality of their video products.

⁴ It may strike some readers as odd that we place such strong emphasis on storytellers retaining control over products resulting from their reminiscence interviews. Our position is the result of drawing a sharp distinction between a study conducted for purposes of research versus a

reminiscence activity. We do not consider intergenerational reminiscence to be "research" in the sense that it consists of a researcher engaged in the search for generalizable information and who is collecting "data" in a systematic manner from subjects of study. In an intergenerational reminiscence activity interviewers and storytellers are *partners* in a shared experience, and any products resulting from this experience cannot be considered to be data that are *owned by a researcher*. As such, we do not believe the storytelling partner should be required to give up control over distribution of his or her own story.

available, what can a project team do to reduce the likelihood that this type of negative outcome will occur? One possibility is to ask the storyteller to think through the likely negative consequences of including this particular story and to caution them against it. But what if the storyteller still insists on including a story in a set of recorded and archived reminiscences when the interviewer has good reason to think that doing so could have negative consequences or result in harm? This represents an ethical dilemma because the ability of the storyteller to exercise autonomy (i.e., they should have control over the contents of their own archived reminiscences) conflicts with the interviewer's obligation to protect the participant from harm. We see no easy way to resolve this conflict, except to say that project personnel also have a stake in the outcome of the project, and that they have the right to exercise their own autonomy by declining to make a life story publically available if they have strong reservations about doing so. In general, the ethical obligation of protection from harm requires us to anticipate and avoid, as best we can, any action on our part that leaves participants in a more negative state (e.g., financially, psychologically, or in terms of their reputation in the community) than if they had never participated. It is appropriate for an instructor/project coordinator to step in at this point to mediate the situation as best they can. Students should not be in the position of negotiating resolutions to complex ethical problems.

Justice

The principle of justice states that both the benefits and costs of participation are distributed fairly among persons eligible to take part in the program. Even when a project has met its ethical responsibilities toward the people who ultimately participate in the program, ethical issues may still arise regarding the fairness of methods used for *selecting participants*. For example, suppose a student-based reminiscence project takes place in an assisted living setting. The administrators of the facility have given their permission for the project to take place, and staff members support the project enthusiastically. Is it fair for staff members or project leaders to recommend only the most outgoing, agreeable, and high functioning residents as participants? In effect, is it ethically acceptable to select older storytellers based on the degree to which they will be easy for students to work with? If we consider students to be participants in the project also, and benefits to students are judged to be just as important as those obtained by older storytellers, then perhaps we are justified in taking this factor into consideration. On the other hand, if only benefits to older storytellers are considered relevant, then limiting recruitment to friendly, agreeable, high functioning residents clearly does not distribute benefits equitably across all categories of residents—a practice inconsistent with the ethical principle of justice.

There is no “one size fits all” solution to a situation like the one described above. Our goal here is simply to make instructors new to reminiscence-based activities aware of these issues and ask them to take the principle of justice into consideration when selecting participants. That being said, one option to address concerns about participant selection is to ask all eligible residents if they are interested in participating, regardless of staff recommendations. There may be student interviewers who would be a particularly good fit to work with more reserved, disagreeable, or lower functioning residents. It may also be the case that the residents who stand to benefit the most from regular contact with interested young people are those who feel the most isolated and lonely in an assisted living setting.

Summary and Closing Thoughts

Our discussion in this paper was designed to provide instructors and students with a brief introduction to three basic principles which experts in the field of ethics consider important when working with human participants: respect for persons, beneficence, and justice. Our intent was not to be proscriptive or inflexible with respect to specific procedures instructors should implement. Every program is unique, and each will have its own set of challenges that organizers will have to navigate. The most we can hope to accomplish in this paper is to provide instructors with a set of ethical compass points to bear in mind. After that, it's up to them to work with students, residential care staff, or others on a set of procedures that meets the needs of their particular project. For instructors interested in leading a discussion on these issues, we have provided a list of sample discussion questions and discussion points in Appendix B.

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Appendix A

Sample Informed Consent Form

Title of Project: Smithville High School Reminiscence Project

We are asking you to participate in a reminiscence program offered by Smithville Public Schools. The program provides a setting for older members of the community to tell stories about their past life experiences. If you decide to participate, we will make a video recording of your conversation with a student volunteer while they ask you questions about events in your life. It will take approximately two hours of your time. Young people from Smithville's Middle School and High School will lead the conversations and record them. You can choose to complete the interview in one session or more than one session.

After the interview is finished the student will edit the recording to create a high-quality digital movie. With your permission, we will donate it to the Smithville Public Library. In the future, community members will be able to watch the interviews at the library. Before the student completes the final version of the movie, we will show it to you to get your instructions for anything you would like the student to change about it, including any parts you would like the student to take out.

This project has no more risk than you may find in daily life. However, there may be circumstances where revealing personal information can bring up negative thoughts and feelings. You can choose not to disclose any information you don't feel comfortable talking about.

Benefits to you for participating in this project may include a positive interaction with a younger person while reminiscing about events in your past. Additionally, you will receive as many copies of your movie as you would like, so you can share them with family members and friends.

It is your choice whether or not to participate in this project. You can end your participation at any time and for any reason. You can withdraw permission to have your reminiscence movie available at the public library at any time.

At this time, please feel free to ask us any questions you have about the project.

If all your questions have been answered and you would like to take part in this project, then please sign below to indicate that you are giving your informed consent to participate.

Signature

Printed Name(s)

Date

I/We have explained the project to the person signing above, have allowed an opportunity for questions, and have answered all of his/her questions. I/We believe that the participant understands this information.

Signature of Witness(s)

Printed Name(s)

Date

Note: A signed copy of this form will be provided to you for your records.

Appendix B

Sample Discussion Questions and Discussion Points

Discussion Question	Possible Discussion Points
How should we select older adults to participate in the project? What can we do to make sure that our selection of participants is fair and equitable?	Do all eligible participants have an equal chance of participating?
Why is it important that the older adults we recruit give their “informed consent” to participate? What information will we need to provide so they can give their informed consent?	Participants have the right to weigh all relevant information when making a decision about whether they would like to participate. • They should have as much control as possible over events that affect them. • Participants should know their role in the project and what the project is trying to accomplish. • Participation is voluntary, and they can end their participation whenever they want. • They should know the risks and benefits from participating. • They should be encouraged to ask questions about the project and their role in it.
What things can you do as interviewers to make sure the older adults in our project know you appreciate their participation?	Tell them you enjoy hearing their stories. • Give them your full attention. • Ask thoughtful follow-up questions that show you’ve been listening attentively.
Why is it important that the reminiscence products we produce are of high quality?	Maximizes the benefit to participants • Making the effort to produce a high quality product shows respect for the participant. • They provide benefits to family members and friends. • What can we do to ensure that our video products are of high quality?
What does it mean to keep information “confidential?”	Definition of confidentiality • Importance of following the participant’s instructions about what information is permissible to share in their reminiscence product • No “gossiping” by talking about the older adult’s stories without their permission • Importance of trust in maintaining a long-term relationship between the student and the older participant • What information provided by participants in our project will not remain confidential?
What does the word “autonomy” refer to?	Autonomy refers to the ability of a person to control events that affect them. • Students can show respect for an older participant’s autonomy by doing such things as obtaining informed consent, allowing older participants to specify what information they want to remain confidential, and giving participants the chance to review and approve any product based on their reminiscences.
What kinds of risks or costs could a participant in our project face? What can we do to reduce likelihood of these negative things happening?	Possible costs resulting from a breach of confidentiality • Importance of effective communication with participants to identify what information is permissible to share and what is not.
What should you do if a person you’re interviewing appears upset or sad about a story they’re telling you?	Let them know that it’s okay to either finish telling their story or to change to another topic, whichever they would like. • If they appear deeply distressed, depressed, or angry, notify the instructor right away so they can speak with the appropriate staff person where the older adult lives or consult a person with expertise in this area (e.g., a person with training in mental health counseling)
Are we doing everything we can to maximize the benefits to participants and minimize potential costs?	Think of possible benefits and risks that haven’t been discussed earlier.