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STU REB Application Form

File #: _____ REB# 2018-05
Full Board or Delegated Review: FULL - MARCH
Decision and Date: Approved April 6/18

Submission Date 14-02-2018 08:47:38

IDENTIFICATION

Principal Investigator Dr Clive Baldwin
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E-mail BALDWIN@STU.CA
Principal Investigator's Academic Status STU Faculty
Department/School Social Work
Are there additional Principal Investigators or Co-Investigators? No

RESEARCH FUNDING

Has funding been requested for this research? No, I do not foresee the need for funding for this study

PROJECT DETAILS

Title of Proposed Research ~~The experience of transableism: A narrative inquiry into the desire to become disabled~~

Research Question(s)

1. To explore the experience of transableism from the perspective of those who identify as such;
2. To explore the ways in which transableism is constructed in the lives of people who identify as such;
3. To develop theoretical ideas as useful resources for mapping and conceptualising the experiences of transabled people;
4. To identify the implications of this investigation for the support, care practices and policies for people so-labelled;
5. To identify how the findings can be fed back into advocacy, professional practice and policy.

Summary of the study for a general audience

This is a qualitative, narrative inquiry into the experience of transableism (Body Integrity Identity Disorder). The study has been going on for 5 years and so now needs REB renewal. The purpose of renewal is so that I might complete the remaining second interviews.

Participants will be interviewed twice about their experience of living with BIID/being transabled - how this affects them, their relationships, their being in the world. In particular, I am interested in how participants create and maintain a stable and viable sense of identity when this very significant, if not dominant, aspect of themselves receives little or no external validation.

Participants will be interviewed twice, and data analyzed through a narrative lens - for example, Bamberg's three-fold identity project (navigating one's identity in terms of continuity/change, sameness/difference, and agency/non-agency). Meta-narratives of ableism, mental health, medical ethics will be explored in terms of how these meta-narratives impact upon the experience of being transabled.

Briefly describe the rationale and purpose of the study

Transableism is a term that refers to the desire to move from being able-bodied to dis-abled through choice rather than happenstance. Just as people who define themselves as 'transgendered' wish to re-align their gender in accordance with their lived experience of who they are, those who are transabled seek to re-align their physical ability with their perceived identity. This may take the form, for example of, self-amputation (see, Berger et al, 2005; Sorene et al, 2006) or seeking elective amputation or spinal cord surgery to paralyze the lower body (see, for example, Blom et al, 2012).

The experience of transableism often results in secrecy, isolation and self-doubt and has, on occasion, led to suicide. The formation and practice of the transabled identity is, therefore, one that requires continual negotiation with respect to others and the physical world with transabled people seeking psychological, social and physical space in which they can accept and express their 'true' identity.

Transableism has only relatively recently received academic attention with 76% of the literature being published in the last 5 years. Given the newness of public and professional discourse on transableism, it is not surprising that there are differing, competing and conflicting understandings and explanations.

This research project seeks to explore how transabled people negotiate an acceptable identity within, around or contra the medical, social and cultural discourses that seek to frame the phenomenon. While there have been partial attempts to understand the experience of transableism (Stevens, 2011; Davis, 2012a, 2012b) and inclusion of brief pieces by transabled people within academic texts (see, section 2 of Stirn et al, 2009) these have been very limited in scope: Stevens discusses the experience of a single subject; Davis relies on postings on a single website (www.transabled.org) and the five contributions by transabled people to Stirn et al are brief, limited in scope and framed within the overarching medical discourse of the book. The proposed study is the first to explore transableism, from the transabled person's perspective, in its individual, social, cultural and discursive aspects.

What new knowledge is anticipated as an outcome of the study and describe the potential benefits of this research

This project will have an impact in a number of areas, within and beyond the social sciences and humanities research communities. Within the social sciences and humanities research communities the study will further our understandings of transableism as a phenomenon, and, in particular, the nature and practice or performance of what is seen, currently, as a transgressive identity – one that transgresses the norms of what is considered acceptable. The analytical framework as a means of exploring transableism may be extended to explore our understandings of other transgressive identities. The project is thus expected to have an impact in its area of study and its theoretical approach.

Beyond these communities the study is designed to raise awareness of transableism and to increase our understanding and acceptance of the experience of transabled people. This will impact on social welfare and health professionals who work with transabled individuals, hopefully (though indirectly) fostering a person-centred focus in professional-service user interactions. Just as the work of healthtalkonline (see, <http://www.healthtalkonline.org/>) has promoted personal stories as a means of enhancing care, this project may do so for transabled people. The literature review and concept analysis will help social welfare and health professionals in their practice by providing a critical overview of the field, and clarification of transableism and related phenomena. The study will also contribute to ethical debate around transableism through detailed cases and concept clarification.

As the first study to focus on the experience of being transabled, it is anticipated that the study will also benefit participants and other transabled people (again, in the vein of healthtalkonline). Dissemination of findings in suitable format via established transabled websites is one means of doing this.

Has this project been approved by any other Research Ethics Board(s)? Yes

At which institution(s)? STU

Is this a Pilot Study? (See TCPS 2 Article 6.11 "exploratory phase" vs. "pilot study") No

Data Collection Begins 14-02-2018

Data Collection Ends 14-02-2018

Analysis Ends 14-02-2019

RISKS AND BENEFITS

Does this research pose more than minimal risk to participants? No

Where will the research be conducted? Please identify where the data collection, surveys, interviews, online, focus groups, and/or other parts of the study involving your research participants, will take place (e.g., on-campus, in community health centres, in participants' homes, at the local high schools, etc.).

Predominantly by Skype/telephone - participants are resident in mainly English speaking countries.

What data collection methods will be used? (Check all that apply)

Interviews

Describe data collection methods (indicated above) in detail, explaining how these will be implemented. If your project involves multiple groups and/or multiple measures or tests or experiments, clearly identify which ones will be used with which groups in your study.

Participants will be interviewed twice. In the first interview they will be asked to recount their experience of transableism, starting with the time they first perceived themselves in this way. The interviewer will then explore more specific areas: self-image, the reactions of others, relationships with family and friends, dealings with professionals, day-to-day accommodation/realization of their transabled self and so on. The interview will be transcribed verbatim, anonymized and returned to the participant for checking, approval and consent for use in the research.

Following initial analysis, questions for the second interview will be established. While the exact nature of these will vary, they will focus on issues of clarification, expansion on areas of interest, links with wider social and cultural factors and matters facing the transabled community more generally. Again, the interview will be transcribed verbatim, anonymized and returned to the participant for checking, approval and consent for use in the research.

Interviews will last, approximately for 1 ½ - 2 hours. They will be audio/video recorded, with consent. Ideally the interviews will be conducted in person but transableism is a relatively rare phenomenon and it is unlikely that enough participants will be recruited locally. If geographical location and cost become prohibitive then interviews will be conducted via Skype or telephone, with interviews being recorded and transcribed as above.

Further data will be obtained via website submissions. The interview questions will be made available via the Narrative Studies website and participants may submit responses. Those participants who are interviewed will also have the opportunity to contribute further via website submissions.

What data will be recorded and in what format?

Interviews will be asudio-video recorded with the permission of participants.

If this study involves persons in contexts of vulnerability or collects sensitive information (e.g. experiences of trauma, loss, illness, or increased harm), please provide details on the researcher's experience and training in dealing with these considerations.

I am aware, however, that the telling of personal stories can be a sensitive matter and that there are power differentials in society that heighten the sensitivity of certain types of story (for example, stories that challenge the existing order or dominant perception). It is possible that some participants might find recounting their experiences difficult at times. If this happens during an interview, the interviewer, (a very experienced narrative interviewer and qualified social worker and counselor) will stop the interview until the participant is ready to continue or decides not to continue. The participant will be offered the opportunity to discuss this with the interviewer and the interviewer will help the participant access other resources if requested.

I am an experienced researcher and social worker, and so am familiar with the issues that can arise when talking about sensitive, personal issues. I have experience in the field of mental health.

Will this research take a participatory approach? Participatory-action research and community-based research may require additional considerations. Attach any relevant documents showing community engagement and/or consultation.

No

Describe your intended participant population

Those identifying as transabled.

Anticipated number of research participants: If you do not have a specific or approximate number in mind, provide estimates of the minimum and maximum number of expected participants. Be sure to include numbers / descriptions for each potential subgroup of participants who may be involved in your project (children, adolescents, university students, adults, seniors, etc).

I have approx 50 participants in the study, with around 12 second interviews still to conduct. It is unlikely that any new participants will be recruited to the study, but should this possibility arise I would wish to include them.

What are the participant exclusion/inclusion criteria and how will they be applied?

Those identifying as transabled. Those over 18, having capacity.

As the project is reliant on volunteer participants coming forward from postings on websites etc, the participants are self-selecting. Given the secretive nature of the population I have to rely on the participant to self-select. If I have reason to question a participant's capacity, I would not include them in the study. The remaining participants to be interviewed all meet the inclusion criteria.

How will you inform interested participants if they do not meet the selection criteria?

This does not apply to existing participants. If any new participants come forward, I would apply the above criteria, and email/telephone the prospective participant to inform him/her, providing an opportunity to discuss the research should s/he so wish.

Type of research participants

Competent Adults

Are you seeking to recruit Indigenous People as research participants?

No

Describe how you plan to recruit participants

The main purpose of the renewal is to allow for the re-interviewing of existing participants. I am not intending to actively recruit new participants, though if new participants come forward, I will include them in the study.

If students are being recruited, are they the Principal Investigator's own students?

No

Please describe how participants will be recruited in a way that will not be coercive, i.e. explain why the participants will not feel coerced.	See above
How will the nature of the research be explained to potential participants? (See TCPS 2 Chapter 3)	See attached information sheet. This is sent to potential participants and/or included in postings for recruitment. Existing participants already understand the nature of the project.
How long will participants have to decide whether they want to participate in the study?	As long as they wish
Method for obtaining their agreement to participate	Oral Consent
Describe the process for obtaining their agreement to participate	Primarily oral consent recorded at the beginning of the interview. Given the secrecy of many transabled people, written consent is difficult to obtain.
In your opinion, are they able to make an informed decision to participate?	Yes
Describe your assessment of the participant's capacity to consent	I have already interviewed the intended participants for this renewal. It is clear from their interview transcripts that they have capacity to consent. New participants will be assessed via prior-to-interview contact via email or telephone.
Will this study involve any waivers of consent?	No
How will participants be advised of their right to withdraw?	See information sheet.
Will inducements still be offered if a participant withdraws?	Not applicable
What will you do if a participant withdraws?	All data pertaining to the individual will be destroyed. Prior to destruction, I will offer to return copies of interviews to the participant.
Is there a point at which participant data can no longer be removed (e.g. post-anonymization)?	Yes
How will participants be informed of this?	Post-publication data cannot be removed. Participants will be informed of this as part of the consent process.
Does this study use misdirection, partial disclosure or deception?	No

Does the proposed research involve accessing identifiable information about participants?

Yes

How do you propose to protect their identifiable information?

While all transcripts will be anonymized prior to use, the research is focused on the lived experiences of individuals and as such is likely to provide a great deal of detail about their lives. This may mean that they could be identified by those who already know them in some capacity. While we cannot preclude any possibility of this happening participants will:

1. be fully informed of this possibility from the outset. If they are concerned about this matter, then they may decide not to participate.
2. have the opportunity to veto any information provided during interviews prior to giving consent for the use of their stories in the research.

If a participant has a publicly available website or blog, and has identified her/himself thereon, then it is unlikely that being identified as a participant in the research will cause any problem.

Participants will be asked whether they wish to receive a copy of the summary of the outcomes of the research. If they do request a copy they will be asked for their names and contact details. These details will be kept separate from any information they supply.

In your opinion, is the data being collected of a personal or sensitive nature?

Yes

What measures will be taken to protect data security and participant privacy rights? (Check all that apply)

Anonymization
Files and equipment kept in locked and secured area
Password protected files and computer equipment (including zip drives and USB keys)
RA/Transcriber Confidentiality Agreements
Storing data on a secure server
Use of pseudonyms
Sometimes participants do not wish to give their real names, which is acceptable. In order to conduct interviews I need very little information - a Skype address of phone number, and a time zone.

Will you be seeking a waiver of confidentiality from participants?

No

Will research results be shared with participants and if so, how will this be done?

All participants are offered the opportunity to review their interview transcripts. All participants are offered the opportunity to receive a summary of the research at its conclusion.

What opportunities (if any) will participants be offered to provide feedback and or correction on their data?

See above

Do any of these methods for obtaining feedback and/or disseminating results raise concerns for participant privacy?

No

Attachment(s)

IDG Transableism Interview schedule.docx

Attachment

IDG Transableism Consent form.docx
IDG Transableism research PIS (2).docx
IDG Transablism consent form for transcript.docx

Attachment

RA Confidentiality agreement copy.docx

Feel free to provide (and/or attach below) any additional information which you feel may be helpful to the REB in evaluating this application. If you are unable to provide the REB with a required document please explain.

I have submitted the prior ethics approval letter in hard copy to the ORS as it is too big a file to be uploaded here.

Attestation

I agree to abide by all policies, procedures, regulations and laws governing the ethical conduct of research involving human participants. I am aware of my responsibility to be familiar with these standards.

I agree to notify the STU REB of any significant change in the methodology or status of the research project (See TCPS 2 Article 6.15 and 6.16)

I agree to comply with requests made by the STU REB during the lifecycle of this research.

For quality control purposes, please rate this form



St. Thomas University

School of Social Work, Fredericton, NB CANADA E3B 5G3

THE EXPERIENCE OF TRANSABLEISM

INTERVIEW CONSENT FORM

CODE:

I have read and understood the information sheet and have had the opportunity to ask questions which have been answered to my satisfaction.

I agree to the interviews for the purposes of the research described in the information sheet.

I understand that I do not have to answer a question if I do not want to and can stop the interview at any time.

I agree to the interviews being audio/video recorded (*delete as appropriate*).

I understand that participation is voluntary and that I may withdraw from the research at any time up until the final report. If I choose to withdraw all information (audio, video, text and personal information) will be destroyed.

Initial to indicate agreement

Agreement:

You have been told that by signing this consent agreement you are not giving up any of your legal rights.

Name of Participant (please print)

Signature of Participant

Date

Signature of Investigator

Date



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USE OF AUDIO/VIDEO RECORDINGS

CONSENT FORM

CODE:

I have read and understood the information sheet and have had the opportunity to ask questions which have been answered to my satisfaction.

I agree to the audio/video recording (*delete as appropriate*) being used for the following purposes (please initial those to which you agree):

- conference presentations,
- educational purpose (eg teaching, seminars, training)s,
- academic publications
- interim and final reports on the website

I understand that I do not have to answer a question if I do not want to and can stop the interview at any time.

I agree to the interview being audio/video recorded (*delete as appropriate*).

I understand that participation is voluntary and that I may withdraw my consent for the use of audio-video recordings at any time before or after the completion of the research project. If I choose to withdraw all information (audio, video, text and personal information) will be destroyed.

Initial to indicate agreement

Agreement:

You have been told that by signing this consent agreement you are not giving up any of your legal rights.

Name of Participant (please print) Signature of Participant Date

Signature of Investigator

Date



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RESEARCH VISIT/OBSERVATION

CONSENT FORM

CODE:

I have read and understood the information sheet and have had the opportunity to ask questions which have been answered to my satisfaction.

I agree to the research visit and to allow the researcher to discuss and observe my activities during that time.

I understand that I can limit access to the areas of my life that can be observed and that I can stop the research visit at any time.

I agree to conversations and activities during the visit being audio/video recorded (*delete as appropriate*).

I understand that participation is voluntary and that I may withdraw my consent for a visit/observation at any time before or after the completion of the research project. If I choose to withdraw, all information (audio, video, text and personal information) will be destroyed.

Initial to indicate agreement

Agreement:

You have been told that by signing this consent agreement you are not giving up any of your legal rights.

Name of Participant (please print)

Signature of Participant

Date

Signature of Investigator

Date



School of Social Work, Fredericton, NB CANADA E3B 5G3

Can I change my mind? And what will happen if I do?

You are free to withdraw at any stage without having to give a reason. If you decide to withdraw then all information you have supplied and can be attributed to you will be destroyed.

Will I be able to see the outcomes of the research?

Yes, you can ask to be put on the list to be sent a summary when it is available. When the research is completed a report will be available on the website.

As the project is quite a lengthy one, annual updates will appear on the website. If you do not have access to the Internet and want to receive these updates, please let us know.

Who do I contact if I have a question or want further information?

Please feel free to contact me by letter, phone or email.

Dr. Clive Baldwin
Rm 313, Brian Muironey Hall
St Thomas University, Fredericton, NB
Canada E3B 5G3
Phone: 506.452.9596
Email: baldwin@stu.ca

If you have questions regarding your rights as a participant in this study, you may contact the Chair of the St. Thomas University Research Ethics Board, reb@stu.ca

If during your participation you have any concerns about the conduct of the research or want to make a complaint, please address these, in the first instance, with myself. If you are not satisfied with the response, you may contact:

Chair
Research Ethics Board
reb@stu.ca

**THE EXPERIENCE OF
TRANSABLEISM**

You are being asked to participate in a research study. Before you decide, it is important that you read the following information and ask as many questions as you want so that you are clear what will be asked of you.

What is the research about?

The proposed research is about the experience of people who define themselves as transabled. We are interested in what it is like for transabled people, their thoughts, feelings, desires, hopes, stories, relationships – indeed any and all aspects of their lives which they are willing to share. It is hoped that the research will promote understanding and awareness of transableism.

Who is conducting the research?

Dr. Clive Baldwin is leading the research. He is Canada Research Chair in Narrative Studies at St Thomas University (STU). The research has been approved by the Research Ethics Board of STU.

Why have I been invited to participate?

You have been invited to participate because you define yourself as transabled.

If I am interested in participating, what should I do?

If you are interested in participating, please contact me, indicating your interest and asking any questions you might have. You can do this by phone, e-mail, or regular mail:

Dr. Clive Baldwin,
Rm 313, Brian Muironey Hall
St Thomas University, Fredericton, NB

What does participating in the research involve?

In agreeing to participate in the research you are agreeing to take part in three interviews, each of approximately 1 ½ - 2 hours in length. The first interview will focus on your experience from the time you first began to see yourself as transabled and you will be able to tell your story in as much detail as you want. The second and third interviews will focus on clarifying and expanding on matters arising therein and on exploring particular aspects of your experience such as relationships with professionals, family and friends and what you have found helpful and unhelpful, and social and cultural issues.

Ideally we would like to interview you in person and interviews would be arranged at a time and place convenient to you and are quite informal. Any out of pocket expenses (e.g. travel costs) will be reimbursed.

If a face-to-face interview is not possible due to geographical location and/or costs we may ask to interview you by Skype or telephone. You will be asked for your permission for the interviews to be recorded. If you would like to see the transcripts of your interviews prior to giving permission for their use, we will send these to you.

In addition, you may be asked whether you would be willing for a researcher to visit you and spend up to five days with you talking about and observing your daily life. **This is entirely voluntary and you can still participate in the interviews even if you do not want to participate in this part of the research.**

We will also ask you for a small amount of personal information (for example, age, gender, ethnicity) that will help in the research – all of which will be kept completely separate from the interview material.

What will happen to the information I provide?

Interviews will be typed word for word (transcribed) and all identifying personal information removed. The information will then be analysed and used in reports, journal articles, conference presentations and educational materials. All information will be edited so as to ensure that you cannot be identified (with the exception of audio and/or video recordings – see below).

All information will be stored in locked filing cabinets and/or password protected computer files. All material will be destroyed after seven years following completion of the research.

Will the information I give be confidential?

Yes. Only those directly involved in the research will have access to the information you give us. Transcribers will be required to sign confidentiality agreements. All information will be treated in confidence, unless you told us about another person being harmed or at risk of being harmed or about an unresolved or future crime.

All identifying information will be removed from the information you give us. You will be sent a copy of the transcript for correction and approval before it is included in the research.

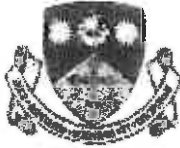
In addition to being asked to agree to being interviewed you will be asked also whether you agree to any audio and/or video recordings being used in conference presentations, for educational purposes, in academic publications or in interim and final reports on the website. **This consent is entirely separate from agreeing to participate in the research and you can still participate in the research even if you do not want the audio/video recordings to be used in this way.** If you agree to these uses of the audio/video recordings we cannot guarantee that you will not be identified from the recording so please think very carefully about this. Once again, you do not have to agree to this— we can work with the typed transcripts alone.

What are the benefits of participating in the research?

While some people find it helpful to talk about their experiences, there will not necessarily be any direct benefits to you individually as a result of participating in the research. The purpose of the research is to help promote awareness and understanding of the issues facing transabled people.

What are the risks of participating in the research?

The risks of participating in the research are minimal. It is possible that some people might become upset when recounting particularly difficult experiences. If this happens the interviewer will stop the interview until you are ready to continue or decide not to continue. You will be offered the opportunity to discuss this with the interviewer and the interviewer will help you access other resources if you would like.



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Confidentiality Agreement

In my capacity as Research Assistant I recognize that at time I will have access to sensitive and private information relating to Dr Baldwin's research. I agree, therefore, that I shall not:

- a) communicate, disclose or make available any such information to any third party;
- b) copy any such information, in any format, except at the direction of Dr Baldwin and for his purposes;
- c) directly or indirectly use, or permit others to use, any such information other than for purposes directed by Dr Baldwin.

The obligations of confidentiality and non-use apply to:

- a) any documents, electronic files or notes relating to any of Dr Baldwin's research projects;
- b) interview recordings (audio and video) and transcripts;
- c) Dr Baldwin's writings, notes, work in progress.

I shall take all measures necessary to secure the confidentiality of any such material by:

- a) not using, reproducing or storing any such information in an externally accessible computer or electronic retrieval system and not transmitting it by any means outside of STU;
- b) maintaining reasonable measures of security for safekeeping any such documentation;
- c) returning upon request all documents and other materials in my possession to Dr Baldwin.

AGREED;

[Name]

Date

Interview schedule

The following are indicative questions for interviews rather than a comprehensive, exhaustive list. While the research is interested in the areas indicated by the following questions, the lead will be taken from the participant, exploring areas of importance

Please tell us about your experience of transableism, perhaps starting from the time you first began to think of yourself as transabled?

How do you express your transableism?

What has helped you in your transableism?

What has hindered you?

How do you see your life as different if you were allowed to become disabled? Personally, socially, politically and so on.

Where, and from whom, do you find support?

How have family and friends reacted? What would you like from family and friends?

How have professionals (eg social workers, doctors, psychologists etc) reacted? What would you like from professionals?

How do you respond to those who would say that transableism is a form of mental disorder, for example body integrity identification disorder?

How do you see transableism's relationship to disability and the disabled community?

How do you see transableism's relationship to transgenderism and transethnicity?

Why do you think that transabled people should have the right to become disabled?

What do you think are the ethical issues involved in transableism?

How do you see the future?

What would you say to others who are beginning to think of themselves as transabled?

Is there anything you want to add, that is of importance in understanding the experience of transableism?