

PAID CAREGIVERS OF RESEARCH PARTICIPANTS WITH DEMENTIA: *the unexplored ethical risks of transposed incentives, involuntary intermediaries, and pre-existing power structures*

Displayed at Canadian Conference on Dementia Hot Topics Virtual Conference, October 2026.

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Background

The Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans 2 (TCPS) discusses a number of ethical issues that are relevant to research involving persons with dementia (PVD), including vulnerability, the use of incentives, power imbalances, informed consent, therapeutic misconception, and conflicts of interest.¹ These issues are usually discussed in the context of the researcher-participant dyad or the researcher-participant-substitute decision maker triad; relationship structures in which the researcher has direct obligations to others and the Research Ethics Board (REB) has direct oversight. (Image 1 and Image 2.)

IMAGE 1: RESEARCH DYAD

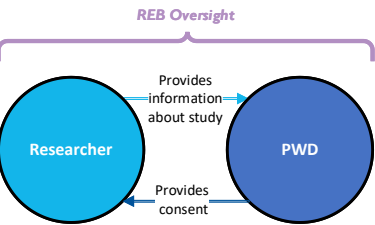
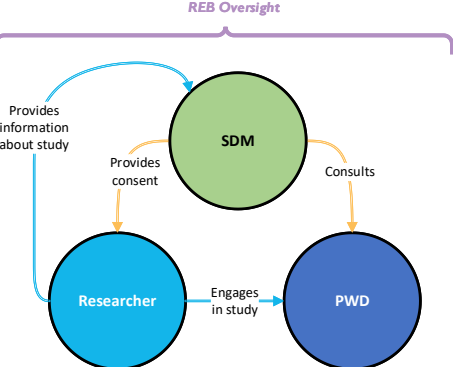


IMAGE 2: RESEARCH TRIAD



A different research dynamic and related ethical issues arise when the PWD also has a paid caregiver (PC) and a substitute decision maker (SDM) who is also the PC's employer (Image 3).

Objectives

- (1) Show that ethical issues stem from the pre-existing relationship structure between the PWD, the PC, and the PC's employer
- (2) Identify the circumstances that make ethical issues more likely to arise from this dynamic
- (3) Explain that these ethical challenges and their origin are not explicitly addressed by the TCPS
- (4) Offer practical suggestions to assist researchers and REBs surface and address these issues in dementia research

Methods/Overview

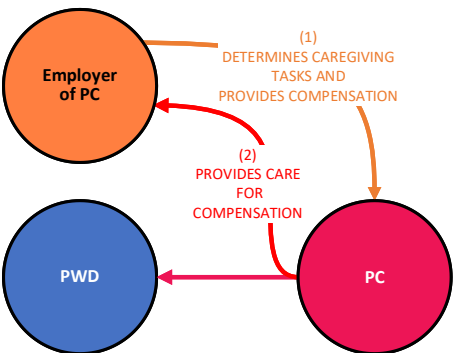
The Care & Compensation Relationship Structure (CCRS)

Some families in Canada hire private caregivers (PCs) to help meet the day-to-day needs of persons with dementia (PVD). While having dementia does not preclude a person's having capacity to care for themselves nor their ability to hire someone for assistance, it is often a third person – a close family member, or someone given authority to act – who takes on the role of employer. In this role, this person negotiates with the PC to identify (1) the tasks to be completed in caring for the PVD and (2) the compensation that will be provided in return. These people and activities are represented in what we call the Care & Compensation Relationship Structure (CCRS). (Image 3.)

Although the CCRS can certainly produce beneficial outcomes for all involved, it must also be acknowledged that it – like any other human relationship structure – can also produce harm. The potential for harm produced by the CCRS will vary depending on the distribution of power and vulnerability among those individuals involved, what other employment options the PC has, what other care options the employer has, and how strong their respective needs for care and compensation are.

Researchers engaging people in this pre-existing relationship structure must be aware of these potential harms and how they can develop in the research context, as we will discuss in the next section.

IMAGE 3: CARE & COMPENSATION RELATIONSHIP STRUCTURE



Ethical issues arising from directly or indirectly engaging the CCRS in research

When a research study engages a PVD who is part of a CCRS, there is great potential for a single person in that structure to take on two roles. Within the CCRS, this person is an employer who determines work-related tasks and provides compensation for their completion; within the research triad, this person is an SDM who becomes informed of the study and provides informed consent on behalf of the PVD. While there are concerns about conflicts of interest here, there are also ethical issues of a different sort.

First, when the employer/SDM (E/SDM) uses the pre-existing CCRS to facilitate the PVD's participation in the study (i.e. by adding research-related tasks to the PC's workload) the study becomes tied to an incentive structure beyond the view, analysis, influence, and control of the REB and the researcher.

Second, the REB's and researcher's authority to intervene in the activities of the CCRS may be limited: the CCRS's purpose is unrelated to research, it is based on mutual agreement between the individuals involved, and it is already governed by other (i.e. non-research-related) guidelines and laws. It is unclear what role the REB or researcher would have in determining the tasks an employer sets out for their employee. In many ways the goings-on of the CCRS are simply not within the jurisdiction of the REB and the researcher to control.

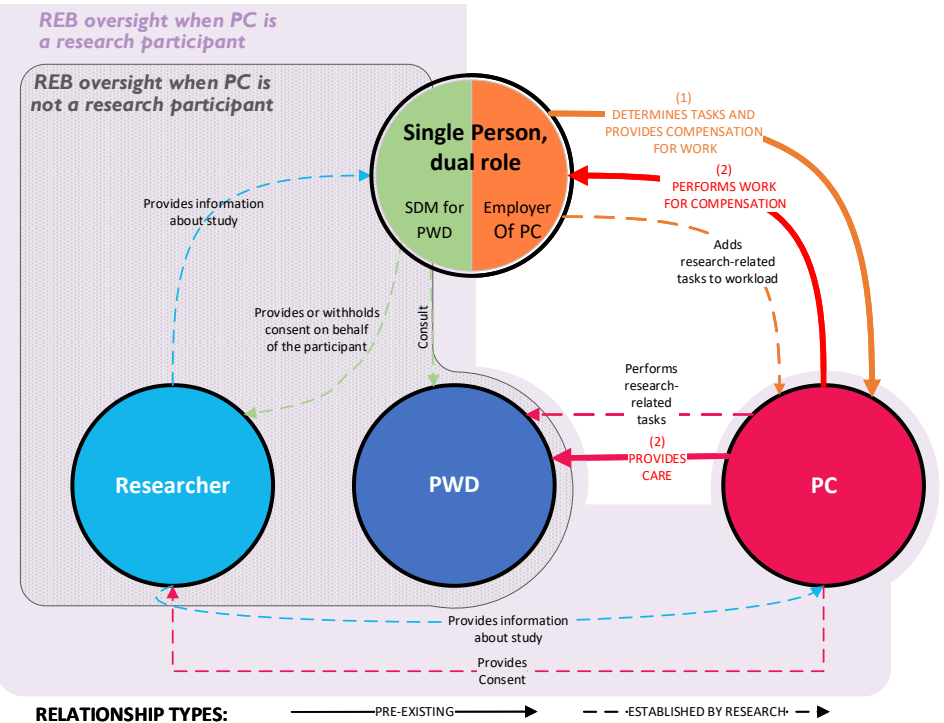
Third, the REB and researcher must also consider that when a PVD is part of a CCRS that already involves vulnerability and power imbalances, or even clearly unethical behaviours (e.g. force, coercion, intimidation), those issues are likely to be replicated within any research activities that make use of the CCRS, directly or indirectly.

The ethical issues that can arise through the direct or indirect engagement of the CCRS in research are complicated and amplified by issues of awareness and legitimate authority to intervene. While we cannot know exactly which constellation of ethical issues will arise when a CCRS is engaged in research activities we can see how the interaction of two things is likely to influence the overall ethical risk. In general, it seems that the E/SDM adding research-related activities to the PC's workload will increase the overall ethical risk, and the researcher engaging the PC as a study participant will lower the overall ethical risk. These effects can likely be explained by two facts: (1) when research activities are transferred to the CCRS they become vulnerable to all of the individual ethical issues that might already exist there and (2) engaging the PC as a participant ensures at least limited oversight of the PC's research-related activities. (Table 1 and Image 4.)

		Employer/SDM	
		Does not add research-related tasks to PC workload	Does add research-related tasks to PC workload
Researcher	Engages PC as a participant in research	Low risk	Moderate risk
	Does not engage PC as a participant in research	Low risk	High risk

TABLE 1: RISK OF ETHICAL ISSUES ARISING FROM ENGAGEMENT OF CCRS IN RESEARCH

IMAGE 4: CCRS ENGAGED IN RESEARCH



What does the TCPS say – or not say – about the CCRS being engaged in research?

At least three elements from the TCPS suggest that consideration and protection should extend to the PC even when they are not participating directly in research:

(1) The risk/harm framework is not limited to participants

The TCPS defines risk as "a function of the magnitude or seriousness of the harm, and the probability that it will occur, whether to participants or to third-parties."² Arguably, a PC who is expected to facilitate the study falls within the class of "third parties" whose harm the REB and researcher are already supposed to be weighing when it assesses the protocol.

(2) "Concern for Welfare" as relational rather than individualistic

The TCPS states "[a] person's or group's welfare is also affected by the welfare of those who are important to them."³ Interdependence of welfare, therefore, is inherent to the Policy's definition of the principle. The explicit requirement to protect the participant's welfare may therefore extend to the protection of the welfare of someone whose labor and relationships are intertwined with the participant's ongoing involvement. In this instance, a caregiver's exploitation or distress is not a separate concern from the participant's welfare.

(3) "Employer" is already identified as a third-party risk category

In discussing the requirement that informed consent be given voluntarily, the TCPS identifies employer relationships – such as that which exists in the CCRS – as a legitimate source of research-related risk requiring active mitigation.⁴ The "trust and dependency" involved in pre-existing relationships can pose a risk to the voluntariness of consent – and REBs and researchers are advised to anticipate and address this dynamic.

These considerations suggest that REBs and researchers *should* be actively inquiring about and considering the CCRS in dementia research; however, the Policy does not provide a specific mechanism – such as a consent requirement, defined obligation, or named category – that would make protections operational.

Results

The potential ethical risks involved in engaging PVD who are already involved in a CCRS require careful reflection and planning by REBs and researchers. Focusing on two issues – one that is more under the control of researchers and REBs, and one that is not – can help guide this further thinking.

First, there is an imperative to increase awareness of when a PVD engaged in research is part of a CCRS, and – if possible – to find out how that relationship structure is or is not engaged in research activities. Without making specific enquiries, the researcher and REB may not even be aware of the PC's involvement in facilitating or carrying out research activities. Increased awareness can come from incorporating questions about caregiving and research activities into the screening activities and the informed consent process. (Table 2.)

Has the protocol identified every point where a PC may perform safety- or data-relevant tasks?	Is the PC's consent to participate sought away from the E/SDM's presence?	Can the PC decline research tasks with no effect on their job?	Does the PC have training in dementia care?
Is SDM consent being treated as sufficient to cover the PC's involvement? If so, is that assumption explicit?	Should consent processes and forms explicitly ask the SDM whether anyone else will be helping with the study?	Would losing this employment position result in a meaningful income loss to the PC, thus creating pressure for continued compliance?	What is the PC expected to do if the PVD refuses to participate at any point?
Does the PC have any escalation path if they notice a problem?	Does the study budget include a line item for PC time or compensation?	Is the PC's immigration status dependent on their employment, making refusal effectively impossible?	Are the research activities like or unlike tasks already carried out by the PC in their caregiving role?

TABLE 2: POTENTIALLY USEFUL ETHICAL REVIEW QUESTIONS TO SURFACE THE ETHICAL ISSUES RELATED TO THE INVOLVEMENT OF CCRS IN RESEARCH

Second, the REB and researcher can look to create legitimate routes for oversight and intervention in research activities that are facilitated through a CCRS. The researcher and REB do not have the authority to manage the relationship between an employer and an employee, but they must find ways to ensure that the role of employer is not used to carry out their research.

Conclusion

Judgment is often required in the ethical evaluation of research. The TCPS itself states that "evaluating the ethics of research involving humans is not, and cannot be, an exact science."⁵ Although the ethical issues that arise in research involving the CCRS are not directly addressed by the TCPS, it is easily argued that researchers and REBs are still responsible to address and manage them.

References:

