

The Group as Support for Caregiver Reflection on Moral Issues

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The Journal of Social Work Values and Ethics, Volume 15, Number 1 (2018)
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Abstract

This article summarizes the evaluation of an Alzheimer patient caregiver psychoeducational group intervention based on a theoretical model of moral responsibility. The moral dimension of responsibility arises as a central component of the caregiving phenomenon as the current fragmenting of the social fabric and relationships to others continues. For a group social worker, taking into account the ethical dilemmas facing caregivers means proposing psychosocial avenues and philosophical guides as responses to distress and to their legitimate quest for meaning in this experience of responsibility towards a loved one.

Keywords: psychoeducational group, moral responsibility, caregivers, Alzheimer disease

Introduction

In this article, we present the findings of an *evaluation of practices* that was carried out in the context of a psychoeducational group intervention project where the aim was to heighten caregiver

awareness of moral responsibility. An examination of the treatment of moral responsibility by philosophers throughout history reveals the vagueness and polysemy of the concept as well as its social and historical uprooting (Métayer, 2001). Moreover, the concept has been and continues to be theorized within the current and longstanding tendency to psychologize human action. Many ethicists base moral responsibility on universal psychological conditions (Sneddon, 2005), a prevalent conceptual framework also in social intervention. Amplification of the impact of individual and psychological dimensions on the interpretation of problematic situations is the subject of intense debate within the discipline (Boily 2014; Moreau & Lapierre, 2011). Cultural, geographical and historical factors all influence the process by which the moral responsibility construct takes shape in individuals; hence the need for the social worker to rethink moral responsibility as a connection between each individual in the group and his or her social context (Sneddon, 2005). As a result, this article begins with an overview of current knowledge on group interventions

designed for caregivers. This is followed by a focus on the theoretical model of moral responsibility underlying the design of the intervention project. Parts three and four present the intervention project and the methodology by which the intervention was evaluated. The results of the evaluation are presented in part five, and the article concludes with a discussion of the contribution of the project to reflect on ethics and practices in social intervention.

Current Knowledge on the Effectiveness of Group Interventions for Caregivers of Relatives With Alzheimer's Disease

As reported in several meta-analyses, numerous psychosocial interventions for the benefit of caregivers have been evaluated (Brodaty, Green & Koschera, 2003; Yin, Zhou & Bashford, 2002), which include group interventions. Group interventions are noted as one of the three social service intervention methodologies with two of these group types particularly preferred for caregivers. First, the aim of the support group is to help members mobilize their coping abilities in order to respond to stressful situations (Toseland & Rivas, 2005). Despite the beneficial effects noted, evaluation reveals that there are only modest reductions of the burden on caregivers (Sörensen, Pinquart, Habil & Duberstein 2002). Second, caregiver educational groups (often called psychoeducational) have been evaluated as well (Kouri, Ducharme & Giroux, 2011; Thompson *et al.*, 2007). The aim of these groups is usually to provide caregivers with standardized information on illnesses, disruptive behaviours and the acquisition of skills for the role of caregiver (Acton & Kang, 2001). While it appears that these groups do contribute to increased knowledge, which is fundamental for fulfilling the role, results are rather modest in terms of improving wellbeing or reducing stress, depression or burden (Devor & Renvall, 2008; Kurtz, Wagenpfeil, Hallaeur, Schneider-Schelte & Jansen 2010), and content is focused primarily on the negative aspects of the role (Carbonneau, Caron & Desrosiers, 2009).

Being largely experimental, evaluative studies of group programs (regardless of whether the group is of the supportive, educational or psycho-educational type) are based on standardized methods of assessing group effects, especially effects on the stress or burden experienced by the caregiver. When such methods are used, the observed lack of conspicuous effects could be due to the complexity of the burden (Cooke, McNally, Mulligan, Harrison & Newman 2001). The interventions selected for evaluation might be poorly adapted to the concerns of caregivers, the variables measured might be irrelevant, and the type of program offered might be unsuitable (Kouri, Ducharme & Giroux, 2011). Burden does appear to have multidimensional causes and ethical dilemmas faced by caregivers may exacerbate the problem (Hugues, Hope, Savulescu, & Ziebland, 2002). In fact, the literature raises questions surrounding the moral dimension of the care experience and its impact on the caregiver (Howe, 2010; Lin, Macmillan & Brown, 2011). The responsibility of looking after a person with Alzheimer's disease involves not only performing domestic tasks or providing care, but also a moral experience comprising affective relations with which responsibilities and obligations are associated (Crochot & Bouteyre, 2005; Éthier, Boire-Lavigne & Garon, 2014; Lin, Macmillan & Brown, 2011). However, the care practices literature has been relatively silent on the highly polysemous notion of moral responsibility (Lindh, Severinsson & Berg, 2007).

Theoretical Model of the Moral Responsibility of Caregivers

In this section, we present the theoretical model proposed by Éthier, Boire-Lavigne, and Garon (2014), which was used for this study. Using this model, the authors contribute to increasing caregiver awareness of better ways of looking after a person with Alzheimer's disease by focusing the social intervention on the moral experience and not only on the functional or negative aspects of the role. According to the authors, the moral responsibility of caregivers consists of six distinct but interrelated dimensions.

Inner transformation

The first component of moral responsibility refers to the nature of the transformation (of the care receiver) from which the moral obligation arises (Éthier, Boire-Lavigne, & Garon, 2014). It is this transformation (affecting the higher mental functions in particular) that compels a caregiver to assume a responsibility, which takes on its full moral dimension largely through the upheaval imposed on the existing relationship.

Transformation of the relationship

For some caregivers, the relationship with the care receiver is transformed positively by introducing a fusional or even symbiotic component. However, some caregivers experience remoteness or even a breakdown in the relationship. In any case, the relationship remains at the centre of the moral responsibility since it tones each decision made by the caregiver and is the basis for assuming responsibility.

Basis for assuming responsibility: Duty, promise, and love

The basis of responsibility refers to the fundamental reasons for which a caregiver looks after his or her loved one. The reasons most often mentioned relate to the naturalness of doing so and to the duty, obligation, and promise to do so. In this context, it is no longer a matter of responsibility in the usual sense. Accepting the role of caregiver involves taking on important ethical and relational issues.

Enabling responsibility: Moral values and ethical dilemmas

Enabling of responsibility refers to the way in which caregivers assume their new role. Being a caregiver involves carrying out tasks that are much more complex than they appear initially, since they involve upholding moral values and resolving ethical dilemmas on a daily basis, for example, locking doors to ensure safety at the cost of compromising some of the loved one's autonomy or dignity.

Response of caregivers to the call to moral responsibility

While caregivers are aware of some obligation to care at the outset, the manner in which they rise to the challenge changes over time. Éthier, Boire-Lavigne and Garon (2014) describe this process in five phases. The first is *resilience*, which is facing difficulties by developing coping strategies (humor, optimism, flexibility...) better adapted to overcoming them. The second, *self-transformation*, involves developing new skills and attitudes, such as taking on the role of nurse, physiotherapist or handyman. The third corresponds to *sacrifice* (of activities, plans for the future or retirement) and *mourning* (including that of his or her still living close relative). The phase of *anticipating limits in the face of responsibility* allows caregivers to foresee an end to their responsibility. Finally, the fifth phase, that of the *emergence of real limits in the face of responsibility*, is the one that requires re-examining the manner in which the caregiver role is assumed. The initial resilience phase thus poses a danger, since even though it is essential for assuming the role, it can lead the unwary caregiver to push him or her self to exhaustion by failing to define reasonable limits of the responsibility.

Owning the responsibility

Throughout this experience, caregivers are inevitably confronted with norms coming from their entourage and from medical professionals on how they should look after their loved one. They then choose whether or not to follow this advice, based on their own experience and knowledge of their loved one, which may involve consequences for which they must assume responsibility.

In other words, the role of caregiver constitutes a moral responsibility because of these six different dimensions to which it refers. These dimensions make up the essential core of the psychoeducational group program presented below.

Psychoeducational Group Intervention Project

Presentation of the project

The project was carried out within the framework of one of the author's Master's degree in social work at Université Laval. The Haute-Côte-Nord/Manicouagan Health and Social Services Centre hosted the group intervention. This establishment of the Quebec health and social services network offers many services to families, children, youth, people with mental health problems and seniors.

The objective of the group was to heighten caregiver awareness of their moral responsibility. It was hoped that by the end of the intervention, caregivers would be able to: 1) initiate a critical thought process regarding their moral responsibility, 2) increase their sense of self-efficacy in the exercise of their moral responsibility, and 3) develop their self-esteem by becoming aware of the importance of their responsibility. The notion of moral responsibility awareness refers less to developing knowledge associated with know-how and terminology (relating to illness, attitudes, communication with the loved one) than to understanding and owning the issues underlying their responsibility with emphasis on appropriate conduct. Increases in the sense of self-efficacy of caregivers as a result of participation in psychoeducational groups have already been demonstrated (Au *et al.*, 2010). To the best of our knowledge, considering this sense in a moral responsibility theoretical framework along with self-esteem and critical thinking is innovative. The main methods used to achieve these objectives were educational activities and discussions promoting the development of mutual aid. The participants were recruited with the help of practitioners who publicized the project and transmitted the coordinates of the student-researcher to potential participants to allow them to contact her on a voluntary basis.

Psychoeducational group programming

The program consisted of six group meetings each lasting an hour and a half. The student and a social worker in the organization where the group was held developed the meeting content using the components of the Éthier, Boire-Lavigne and Garon (2014) model of moral responsibility. For the theme of the care receiver transformation, the title of the first meeting was "*I sometimes have difficulty recognizing my loved one. How is this possible?*" For the theme of transformations of the relationship, the second encounter was entitled "*What is to become of our relationship now?*" The third meeting ("*Why did I accept this caregiver role?*") addressed the basis for taking on the responsibility by focusing on the various motives suggested by caregivers. This meeting also shed light on the individual, family and social contribution of their role as well as the strengths and limitations of the commitment. The aim of the fourth encounter ("*Why do I feel so much frustration?*") was to explore the idea of enabling responsibility through the values conveyed during the accompaniment of their loved ones and the ethical dilemmas encountered in connection with these values. The phases of caregivers' responses to the call to responsibility were explored during the fifth meeting ("*Is my role as caregiver an until-death contract?*") Finally, a sixth meeting shed light on the theme of owning the responsibility. "*It is up to me to define my role and responsibilities as a caregiver.*"

Methodology for the Evaluation of the Group Intervention

Evaluation of the intervention involved measuring its effectiveness in a context of normal practice such that the query focused on effectiveness of use (Champagne, Brousselle, Contandriopoulos, & Hartz 2012). In view of the intervention context, the evaluation was internal (Ridde & Dagenais, 2012), meaning that it was conducted by the actors involved in the intervention, namely the student-researcher, in order to "maintain continuous and inquisitive monitoring of the work being carried out" (p. 436).

Description of the tools of evaluation

Quantitative measurement scales were administered before and after the intervention to assess the self-efficacy sentiment and self-esteem. We used the self-efficacy sentiment scale of Bandura (2003), validated in French by Ducharme et al. (2003) among family-member caregivers of elderly persons with dementia in Quebec. To evaluate the concept of self-esteem, the Rosenberg scale (1965) validated in French by Vallières and Vallerand (1990) was used. The results obtained using these scales are based on the change in direction (increase, decrease, stable) rather than on statistical significance. The observations of the student-researcher were noted in a log to add qualitative data providing additional information on participants' sense of self-efficacy and self-esteem.

Collection of qualitative data was recommended in order to measure the critical thinking component through individual interviews. The interviews were recorded with the participants' written consent and transcribed verbatim for content analysis (Mayer, Ouellet, Saint-Jacques, & Turcotte, 2000). Participants were interviewed before and after the group intervention. The interviews consisted of evaluating difficulties experienced, the positive aspects and the contributions of the role. The log kept by the student-researcher also made it possible to include observations made regarding the critical reflection of each group member.

Ethical considerations

The ethical dimensions of this intervention project were addressed using a written and signed contract certifying the informed consent of each caregiver to take part in the intervention and guaranteeing the confidentiality of the statements made during the meetings and interviews. The student-researcher also signed a commitment to confidentiality statement, as requested by the organization hosting the intervention, in compliance with the institution's standards. In addition, the project was in compliance with the ethical standards, including those relating to record keeping, of the OPTSTCFQ (*Ordre*

professionnel des travailleurs sociaux et des thérapeutes conjugaux et familiaux du Québec, i.e. the Quebec Social Workers and Marriage and Family Therapists professional association). A file was created for each participant and a group file was created (Turcotte & Lindsay, 2014). Finally, the individual and group files were kept under lock and key throughout the intervention.

Results

In order to maintain the anonymity of the participants, the socio-demographic data are grouped such that the group members cannot be identified. Four women and two men, aged 48 to 84, participated in the group. Each participant had been caring for a spouse, stepfather or mother for approximately six years. Two of the participants were not living with the care receiver, who had been living in an extended care facility for two years. These participants were nevertheless fully present, since they were spending their days entirely with that person.

The results are presented for the group as whole. It should be borne in mind that the first objective was to develop the self-esteem of the caregivers. Table 1 suggests that most of the participants achieved this objective. The evaluation revealed improvements in self-esteem ranging from 4 to 7 points for four of the six participants.

The logged observations tended to corroborate this measurement. Group members

Table 1
Participant self-esteem as measured using the Rosenberg scale

Participant	Before intervention	After intervention	Difference
1	28	35	+ 7
2	35	35	None
3	36	40	+ 4
4	34	35	+ 1
5	26	29	+ 3
6	33	37	+ 4
Average	32	34.7	+ 2.7

congratulated each other for their good moves and successes and were able to attribute qualities to themselves as well as to others. Before the meetings began, some of the caregivers found it difficult to identify situations in which their role had made them proud of themselves, which was no longer the case at the end of the meetings.

The second objective was to increase the sense of self-efficacy of each group member. The results obtained using the Bandura scale (2003) presented in Table 2 show a slight improvement regarding this sentiment. The observations noted in the student’s log suggested that this objective had been achieved in general. Participants recognized that they were, at the end of the program, better equipped with solutions when faced with various difficulties, and all indicated that their participation in the group had facilitated the learning of new practical skills. In addition, the moral responsibility theoretical model chosen for the group was able to solicit practical skills not included in the measurement tool, such as mobilizing one’s own personal resources in order to cope with the care receiver’s condition.

The final objective for the caregivers was to initiate a critical reflection regarding their moral responsibility towards their loved one. In order to achieve this, they had to identify the difficulties encountered in exercising their role, the positive aspects and the contributions of their role. A summary of the results is presented in Table 3. During the

post-group interview, the participants expressed their new awareness of the health consequences of their caregiving responsibilities, the sacrifices they had to make, and their personal limitations. At the same time, their statements suggested that they had increased their awareness of positive aspects (proximity and intimacy) experienced through their moral responsibility. Feelings of gratification and self-realization were also mentioned repeatedly where their responsibility was concerned. Finally, it was apparent that their perception of the caregiving role had changed after the intervention. At the pre-group meeting, two participants did not perceive themselves as caregivers, viewing their role as natural and ‘going without saying’. In the post-group interview, each participant recognized his or her role as caregiver, and mentioned the resulting contributions to family and social wellbeing. In summary, the participants showed a deeper critical reflection on their moral responsibility after the group intervention. The data gathered from the logged observations also support these findings.

While it appears that the group achieved these objectives, it is important to remain critical of these outcomes. It would be premature to conclude on the basis of this single intervention project that a psychoeducational group based on the moral responsibility model contributes substantially to increasing caregiver self-esteem, sense of self-efficacy and critical awareness of the role. In the present case, the feeling of self-esteem and self-efficacy was already high at the beginning of the group intervention. Moreover, without a control group, there is no proof that the effects measured were due entirely to the intervention. A causal relationship cannot be established from this study. A broader study therefore needs to be carried out in order to validate these results. This study, nevertheless, draws attention to the possibility that caregivers in support

Table 2
Participant self-efficacy/practical skills as measured using the Bandura scale

Participant	Before intervention	After intervention	Difference
1	3.1	3.8	+ 0.7
2	3.5	3.5	None
3	3.5	4	+ 0.5
4	3.7	3.7	None
5	2.2	2.8	+ 0.6
6	2.9	3.4	+ 0.5
Average	3.15	3.5	+ 0.35

Table 3
Change in critical thinking of caregivers with regard to their moral responsibility

Themes discussed	Results after intervention
Difficulties encountered	<ul style="list-style-type: none"> • Awareness of the scope of responsibilities • Awareness of the possible health consequences of necessary sacrifices and personal limitations.
Positive aspects	<ul style="list-style-type: none"> • Feeling of gratification and self-realization • Awareness of the closeness of and intimacy created by the care relationship
Contribution of the role of caregiver	<ul style="list-style-type: none"> • Identifies with the role of caregiver (sees him or her self as such) • Recognizes the contribution to family (relief felt by relatives) and to society (valuable work without pay) inherent in the role

groups would benefit from examining the theme of moral responsibility, a notion rarely broached in the context of group interventions.

Discussion of the Results: Contribution of the Project With Regard to the Reflection on Ethics and Practices in Group Social Interventions

Few group interventions address the ethical aspects of caregiving. However, the commitment to care for a loved one suffering from an illness is a unique moral experience recognized in the literature (Crochot & Bouteyre, 2005; Lin, McMillan & Brown, 2011). Because the care receiver, vulnerable in his or her otherness, solicits the caregiver directly, the caregiver's role stems in part from a moral injunction to help (Éthier, 2012). This moral responsibility is renewed daily and comes loaded with ethical dilemma, notably in relation to maintaining the dignity, integrity, autonomy and security of the assisted person, but also due to the particulars of the helper-assisted relationship and the limitations felt by the caregiver. However, the caregiver remains free at least in theory to honour the responsibility or not, indeed to negotiate or delegate it (Gagnon, 2006). The caregiver can thus experience ethical tension when he or she gets the paradoxical feeling that the responsibility is inescapable yet negotiable.

The social and cultural context gets mixed in with the moral distress of the caregiver, due to the disintegration of normative and social

references as well as the fading moral conventional wisdom that characterize our hypermodern societies (Castel, 2006; Lyotard, 1979). What are the current meanings of notions such as selflessness, sacrifice, duty, commitment, love and reciprocity, all of which are motivators for some caregiving relatives, especially older ones (Éthier, 2012)? We argue that the moral responsibility of a

caregiver is not just a simple epiphenomenon of the burden notion studied so widely in informal care research (Lavoie, 1999), but rather a central component of the caregiving phenomenon (Éthier, 2012), one that is emerging as the current fragmentation of the social fabric and relationships to others continues. For the group social worker, taking into account the ethical dilemmas of caregivers also means offering them psychosocial avenues and philosophical guides as responses to their distress and their legitimate quest for meaning in this experience of responsibility towards their loved ones.

This psychoeducational group intervention project draws its inspiration from the will to contribute to initiating critical thought among caregivers facing their moral responsibility. However, understanding and implementation of these ethical issues cannot be reduced to an exercise of reason. They have psychosocial implications that require both rational and affective responses. Analysis of the present intervention project reveals a potential for positive impact on caregivers. This project highlights the need for further investigation of the contribution of ethical reflections in the context of group intervention. One interesting approach would be to evaluate the practice of community philosophical research (CPR). Inspired by American philosopher Matthew Lipman (1976), this approach is intended to create conditions that allow individuals to think by and for themselves with diligence and creativity (Sasseville, 2000).

Caregivers who were participating in a group could perhaps use the CPR method together to co-construct their thoughts and moral responsibility towards loved ones in a common process of search for meaning (Gagnon, 2011). Participants could then develop ways of thinking (reasoning, searching, defining, interpreting) and attitudes (astonishment, respect for others, examining possibilities, etc.) that favour understanding and clarification of the ethical issues they face (Sasseville, 2000, 2011). However, the benefits of combining philosophical and psychosocial dimensions in the group intervention context remain to be seen. The present intervention project is an addition to the list of case studies suggesting that this association may be worth examining more closely (Cinq-Mars, 2005; Gagnon, 2011; Hamel, 2010).

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