



Gender differentials on the health consequences of care-giving to people with AIDS-related illness among older informal carers in two slums in Nairobi, Kenya

Gloria Chepngeno-Langat^{a*}, Nyovani Madise^b, Maria Evandrou^a and Jane Falkingham^c

^aCentre for Research on Ageing, University of Southampton, Southampton, UK; ^bSchool of Social Sciences, University of Southampton, Southampton, UK; ^cESRC Centre for Population Change, University of Southampton, Southampton, UK

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Informal caregivers, most often older people, provide valuable care and support for people ill due to AIDS, especially in poor-resource settings with inadequate health care systems and limited access to antiretroviral therapy. The negative health consequences associated with care-giving may vary depending on various factors that act to mediate the extent of the effects on the caregiver. This paper investigates the association between care-giving and poor health among older carers to people living with AIDS, and examines potential within-gender differences in reporting poor health. Data from 1429 men and women aged 50 years or older living in two slum areas of Nairobi are used to compare AIDS-caregivers with other caregivers and non-caregivers based on self-reported health using the World Health Organization disability assessment (WHODAS) score and the presence of a severe health problem. Women AIDS-caregivers reported higher disability scores for mobility and the lowest scores in self-care and life activities domains while men AIDS-caregivers reported higher scores in all domains (except interpersonal interaction) compared with other caregivers and non-caregivers. Multiple regression analysis is used to examine the association of providing care with health outcomes while controlling for other confounders. Consistently across all the health measures, no significant differences were observed between female AIDS-caregivers and female non-caregivers. Male AIDS-caregivers were however significantly more likely to report disability and having a severe health problem compared with male non-caregivers. This finding highlights a gendered variation in outcome and is possibly an indication of the differences in care-giving gender-role expectations and coping strategies. This study highlights the relatively neglected role of older men as caregivers and recommends comprehensive interventions to mitigate the impact of HIV and AIDS on caregivers that embrace men as well as women.

Keywords: caregivers; health impact; older people; urban; Sub-Saharan Africa

Introduction

Long-term care for people with AIDS (PWA), the leading cause of illness and death among adults in Sub-Saharan Africa (World Health Organization [WHO], 2008), is largely in the hands of informal caregivers who bear a great burden resulting in direct and indirect effects on their mental and physical health. Older people in Sub-Saharan Africa provide the bulk of the care for PWA (Ntozi, 1997). Women in particular have largely been portrayed as central in the care and support for PWA (Baylies, 2002; Moller, 1997; Nyambedha, Wandibba, & Aagaard-Hansen, 2003) and the role of older men as caregivers has received relatively little attention in the literature. This paper aims to fill this gap in the literature by highlighting the role of men and women in care-giving to PWA-related illness. The paper also investigates the association between care-giving and poor health outcomes by comparing self-reported health of

non-caregivers with caregivers to PWA-related illness and whether this varies by gender.

Studies which have compared health outcomes between men and women caregivers report mixed findings with more studies pointing to worse health outcomes and perceived higher levels of burden for women compared with men (Kiecolt-Glaser, Dura, Speicher, Trask, & Glaser, 1991; Miller & Cafasso, 1992). These gender differences have however been challenged as “a research artefact rather than a fact” (Kramer, 2002; Miller & Cafasso, 1992) especially in self-reported health outcomes. Men and women tend to report feelings of distress differently, with women more likely to report higher levels of distress or health outcomes compared with men (Pinquart & Sorensen, 2006; Stoller, 2002). Between-gender comparison would therefore often conclude that women have more distress or poorer health outcomes compared with men even though men and women may undergo the same level of stress or health outcome (Lutzky &

*Corresponding author. Email: tete@soton.ac.uk

Knight, 1994). Previous analysis from the study (Kyobutungi, Ezeh, Zulu, & Falkingham, 2009) found women affected by HIV and AIDS through caregiving and loss of support reported significantly poorer health compared with men and no attempt was made to investigate gender differentials per se. In the current paper, we conduct within-gender comparison by contrasting women affected by HIV and AIDS with women who have not been affected, and conduct similar analysis with the men. This acknowledges inherent gender differences and takes into consideration gender-based attributes in self-reported health where women tend to report poorer outcomes compared with men.

Study context, data, and methods

Study design and data

The study was carried out in two slum areas of Nairobi, Kenya. Urban areas of Kenya have a higher HIV and AIDS prevalence rate compared with the rural populations (NASCOPI & Ministry of Health, 2008) with slum areas exhibiting higher prevalence compared with the city as a whole (Ziraba et al., 2010). Stigma and discrimination is still widespread in large parts of Africa, including the slums hindering access to care and support including access to antiretroviral therapy (Merten et al., 2010).

Data are drawn from a population-based study that seeks to investigate the wellbeing of older people living in the slums. The study, "Survey on social, health and overall wellbeing of older people", is nested within a demographic surveillance system (DSS) which follows up the population of usual residents of the two slum areas. One of the specific objectives of the study relevant to this paper was to look at possible mechanisms through which HIV and AIDS affects older people. All people 50 years and older who were resident in the DSS during the round of update preceding the survey were eligible for interview. The response rate was 79%. The survey was conducted between November 2006 and January 2007 using interviewer-administered questionnaires. The survey data are combined with routine socioeconomic and sociodemographic information collected over the same period (September–December 2006). A total of 1429 older people interviewed in the survey had matching socioeconomic and sociodemographic information.

Health measures

Health status was measured using two indicators: (1) the WHO Disability Assessment Score (WHODAS-

12); and (2) presence of a severe illness or morbidity in the 3-month period before the interview.

The WHODAS-12 is a multidimensional measure that assesses day-to-day functionality or disability at the physical, personal, and social levels. WHODAS was designed as a generic disability measure and not tailored for a specific disease or age (WHO, 2009). WHODAS is based on six different domains: understanding and communication (cognition); getting around (mobility); self-care (hygiene, dressing, eating alone); interpersonal interactions (getting along); life activities (domestic responsibilities and work); and participation in society (community activities). The participants were asked to assess 12 functionality items on a five-point Likert scale and the question were phrased in the manner "*In the last 30 days, how much difficulty/problems did you have with ...*". A score for each of the domains was generated by recoding the 12 items with a weight of either 2 or 4 as the maximum possible score which is then summed and converted to a percentage to allow comparison across domains. The resulting score therefore ranges from 0 to 100 with higher scores indicating more functional impairment. The overall disability score is an aggregate of the six domains thus combines both physical and psychosocial dimensions of disability. This paper unpacks the composite score to assess if there are differences in the direction of effect on the individual components that make up the overall disability score by recognising the multifaceted nature of disability. Caring for someone with a chronic condition can be a risk factor as it can impact on functioning or lead to an acceleration of decline in functionality (Vitaliano, Young, & Zhang, 2004).

To assess the presence of disease or general poor health the participants were asked the following question "*what do you consider to be the most severe health problem you have currently?*" If the respondents mentioned more than one health problem, they were asked to state one they considered to be the most severe.

Data analysis

The WHODAS disability scores were treated as continuous variables and summary statistics (mean and standard deviations [SDs]) are presented comparing caregivers with non-caregivers. To investigate differences taking into account other explanatory factors, multiple ordinary least squares (OLS) linear regression models were fitted for each of the six functionality and disability domains, in addition to the overall disability score. The second explanatory variable, presence of severe illness or health problem, is a binary variable indicating whether or not a person

reported having what they considered as a severe health problem. A multiple logistic regression was fitted and the odds ratios of reporting a severe health problem are presented. Factors that are known to influence health (age, marital status, education level, income, and wealth status) are controlled for in the models. Separate models were fitted for females and males and the significance level was defined as $p < 0.05$.

Definition of a caregiver

A caregiver was classified as someone who, at the time of the interview, was providing financial, instrumental, psychosocial, or nursing care to a person with a chronic illness (defined as any illness that had persisted for 3 months or longer) or someone who had provided care to a person with a chronic illness at any other time during the three years preceding the survey. In order to isolate care recipients who had an AIDS-related illness, an indirect approach was used. This approach is an adaptation of the WHO's AIDS case definition which categorises a person as having developed AIDS if he or she presents with at least two of the major signs of an AIDS case in combination with at least one of the minor signs. Overall, the WHO definition has very high specificity but low sensitivity. The presence of these major conditions or illness usually indicates advanced progression from asymptomatic HIV stage to full-blown AIDS (Grant & De Cock, 2001). This study categorised care recipients who were reported to be ailing from at least one of the major signs associated with an AIDS case as having an AIDS-related illness.

Results

Sociodemographic characteristics of study participants

Table 1 presents the sociodemographic characteristics comparing AIDS-caregivers, other caregivers, and non-caregivers. The median age for the overall population is 56 years, however, the men are relatively younger compared with the women by three years. Among the women, AIDS-caregivers and other caregivers have very similar mean ages (56.3 and 56.6, respectively) which is significantly different from non-caregivers with a mean age of about 62 years. The three groups were also significantly different in terms of the highest education level attained. For instance, a higher proportion of AIDS-caregivers (18%) had secondary education or higher, compared with only 4% of other caregivers and about 5% of non-caregivers. There was no difference between the comparison groups of women with regards to marital status. The men's

groups, however, were not significantly different in age and marital status. Unlike the women, where a higher proportion of AIDS-caregivers had secondary education or higher, almost similar proportions of men who were AIDS-caregivers (18%), other caregivers (17%), and non-caregivers (18%) had secondary education or higher.

Characteristics of the care episode for AIDS-caregivers

About 10% (143) of older people reported to be providing or to have provided care to someone with a chronic illness. Out of the 143 carers, 47% (67) were classified as caring for someone with an AIDS-related illness (AIDS-caregivers). The average duration of care-giving for the AIDS-caregivers was 30 months with men generally providing care for longer durations compared with women (38 months vs. 29 months, respectively). This arose largely due to gender differences in care-giving roles with women mainly providing nursing care and assistance with instrumental care while men mainly provided financial care. Demand for financial care may begin at the onset of the illness due, for instance, to medical expenses and the need for support towards living expenses during bouts of illness unlike nursing care which is needed at the symptomatic or AIDS stage of the infection (Knodel & Im-em, 2004). The different forms of care notwithstanding, all forms of care can be a source of burden and stress on the care-giver hence a cause for negative health outcomes.

Functionality/disability scores

Table 2 shows the summary statistics for the disability domains scores and the overall score for women and men by their care-giving experience. Overall, men reported lower disability scores for all the domains compared with women. The highest disability was reported in the mobility domain for both men and women (22.0 ± 23.3 for women and 9.7 ± 16.7 for men) followed by life activities (15.6 ± 23.3 for women and 8.4 ± 17.1 for men) and cognition domains (10.2 ± 15.6 for women and 5.7 ± 11.8 for men), respectively. The lowest disability was reported for self-care (4.2 ± 12.9 for women and 1.9 ± 7.8 for men).

Men who were AIDS-caregivers reported the highest mean disability scores across all the domains (except participation in society) compared with other caregivers and non-caregivers. For instance the AIDS-caregivers recorded a mean disability score of 18.5 in the mobility domain compared with 14.0 among other caregivers and 9.0 for non-caregivers. Similarly, very high disability scores were reported by

Table 1. Sociodemographic characteristics of HIV-caregivers, other caregivers and non-caregivers.

	HIV-caregivers	Other caregivers	Non-caregivers	Total
Women				
Age group**				
50–54	39.4	54.2	35.3	36.3
55–59	36.4	16.7	18.6	19.6
60 +	24.2	29.2	46.1	44.1
Mean age***	56.3	56.6	61.6	61.1
Education level**				
No education	45.5	20.8	51.3	49.6
Primary	36.4	75.0	44.2	45.0
Secondary or higher	18.2	4.2	4.6	5.3
Marital status				
Not married	57.6	70.8	69.5	68.9
Currently married	42.4	29.2	30.5	31.1
Most recent employment status				
Unemployed	36.4	41.7	35.8	36.1
Runs own business	48.5	50.0	56.2	55.5
Employed (informal)	9.1	4.2	6.1	6.2
Employed (formal)	6.1	4.2	1.8	2.1
<i>N</i>	33	24	505	562
Men				
Age group				
50–54	47.1	42.3	43.9	43.9
55–59	14.7	30.8	27.3	27.0
60 +	38.2	26.9	28.8	29.1
Mean age	58.4	58.0	58.0	58.0
Education level				
No education	11.8	5.8	21.3	20.0
Primary	70.6	76.9	61.1	62.4
Secondary or higher	17.7	17.3	17.7	17.7
Marital status				
Not married	11.8	3.9	11.1	10.7
Currently married	88.2	96.2	88.9	89.3
Most recent employment status				
Unemployed	23.5	19.2	12.8	13.6
Runs own business	23.5	40.4	41.2	40.5
Employed (informal)	32.4	32.7	29.1	29.4
Employed (formal)	20.6	7.7	16.9	16.5
<i>N</i>	34	52	781	867
Total	100.0	100.0	100.0	100.0

Note: Chi-square test for between care-giving differences and *F*-test significance levels *** < 0.001; ** < 0.01; * < 0.05. Source: Authors' analysis of NUHDSS Individual Data File, 2006.

AIDS-caregivers in the life activities domain which was about twice (16.0) the score reported by other caregivers (8.1) as well as the non-caregivers (8.2). Among the women however, there is no consistent pattern emerging across the domains. Evidently, AIDS-caregivers relative to other caregivers and non-caregivers reported the highest disability scores in mobility and interpersonal domains but lowest in cognition, self-care and life activities.

Table 3 presents the results of the multiple regression, modelling the effects of providing care on the different functionality domains and the overall

disability score. Different models are presented for women and men, respectively. Older people who were not providing care or had not provided care over the reference period (non-caregivers) are the reference category.

The regression results for women show no significant differences between AIDS-caregivers and non-caregivers in reporting disability across all the domains after adjusting for known covariates (age and socioeconomic indicators). For the men however, AIDS-caregivers had significantly higher disability scores for the mobility ($p < 0.01$), interpersonal

Table 2. Mean and SD of disability domain scores by care-giving experience for women and men.

	HIV caregivers	Other caregivers	Non-caregivers	Total
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
Women				
Mobility	26.6 (25.7)	24.7 (26.2)	21.6 (23.0)	22.0 (23.3)
Cognition	8.6 (14.3)	9.2 (16.4)	10.3 (15.6)	10.2 (15.6)
Self-care	2.2 (7.9)	3.1 (12.2)	4.4 (13.2)	4.2 (12.9)
Interpersonal	11.8 (13.0)	8.2 (11.7)	9.9 (14.8)	9.9 (14.5)
Life activities	14.5 (20.7)	18.4 (27.7)	15.5 (23.1)	15.6 (23.3)
Participation in society	6.6 (17.1)	5.3 (15.6)	9.3 (22.7)	8.9 (22.1)
Overall disability	12.8 (11.3)	12.2 (14.1)	12.3 (13.5)	12.3 (13.4)
Men				
Mobility	18.5 (21.3)	14.0 (19.5)	9.0 (16.1)	9.7 (16.7)
Cognition	10.0 (16.6)	6.0 (11.0)	5.5 (11.5)	5.7 (11.8)
Self-care	2.3 (8.3)	1.3 (5.1)	2.0 (8.0)	1.9 (7.8)
Interpersonal	8.3 (14.9)	4.0 (8.3)	5.2 (10.6)	5.2 (10.7)
Life activities	16.0 (23.0)	8.1 (14.9)	8.2 (17.0)	8.4 (17.1)
Participation in society	2.0 (9.9)	1.1 (7.4)	4.3 (15.4)	4.0 (14.8)
Overall disability	10.4 (11.8)	6.5 (7.9)	5.9 (9.3)	6.1 (9.4)

Note: SD shown in parenthesis.

interaction ($p < 0.05$), life activities ($p < 0.001$), and the overall disability score ($p < 0.01$) compared with non-caregivers. The direction of association between HIV care-giving and the health domains is not consistent across the domains for men as well as women. For instance, women caregivers were less likely to report disability with all the health domains except for mobility whereas the men were more likely to report disability with cognition, mobility, self-care, and life activities and less likely to report disability with interpersonal and participation in society. Both men and women AIDS-caregivers reported higher disability scores with mobility and the overall disability score.

Differentials in illness and morbidity

A higher proportion of AIDS-caregivers (84%) reported having a severe health problem at the time of the interview compared with other caregivers (69%) and less than half (43%) of those who were not providing care. Results of the multiple logistic regression models for women and men to predict the odds of reporting a severe health problem are presented in Table 4. Similar to the disability domains, men who were AIDS-caregivers had significantly higher odds of reporting a severe health problem compared with non-caregivers after adjusting for age and other known confounders. Men who were AIDS-caregivers were almost eight times (confidence interval [CI] 2.95–21.53) more likely to report a severe health problem compared with non-

caregivers. On the contrary, differences among women were not statistically significant.

Discussion and conclusion

The care for PWA in Sub-Saharan Africa is provided largely by informal caregivers and older people provide the bulk of the care and support (Ntozi, 1997). Care-giving to a person with a terminal illness apart from being physically demanding on the caregiver, can lead to negative health consequences (Vitaliano, Zhang, & Scanlan, 2003). In this study, the health of men and women who were providing care to someone with an AIDS-related illness, those providing care to people with other chronic ailments, and non-caregivers are compared. The assumption was that caregivers would present with poorer health outcomes compared with non-caregivers. In particular, it was assumed that AIDS-caregivers would be worse off as a result of factors such as stigma towards PWA coupled with the long debilitating nature of the disease.

Gender and care-giving

A previous study found that older people who had been affected by HIV and AIDS either indirectly or directly reported poorer health than those not affected. Women also reported worse health compared with men (Kyobutungi, Ezech, Zulu, & Falkingham, 2009). This paper examined the association between care-giving and health by conducting within-gender

Table 3. Results of multiple linear regression models of disability domains for women and men.^a

	Women		Men	
	Coefficient (standard errors)	P-value sign	Coefficient (standard errors)	P-value sign
Model 1: Mobility				
Non-caregivers ^b				
Other caregivers	8.686 (4.515)	NS	6.256 (2.204)	**
HIV-caregivers	6.806 (3.948)	NS	8.407 (2.661)	**
Constant	-25.986 (10.861)		-19.987 (6.446)	
R ²	11.4		11.8	
Model 2: Cognition				
Non-caregivers ^b				
Other caregivers	0.971 (3.013)	NS	2.165 (1.632)	NS
HIV-caregivers	-1.028 (2.634)	NS	3.102 (1.971)	NS
Constant	-7.655 (7.248)		0.885 (4.774)	
R ²	8.7		4.2	
Model 3: Self-care				
Non-caregivers ^b				
Other caregivers	2.234 (2.523)	NS	-0.019 (1.007)	NS
HIV-caregivers	-0.415 (2.191)	NS	1.025 (1.229)	NS
Constant	-2.848 (5.995)		-4.200 (2.925)	
R ²	6.1		4.3	
Model 4: Interpersonal interaction				
Non-caregivers ^b				
Other caregivers	0.917 (2.762)	NS	-0.490 (1.439)	NS
HIV-caregivers	3.326 (2.415)	NS	4.056 (1.738)	*
Constant	-6.305 (6.645)		-12.911 (4.210)	
R ²	9		7.7	
Model 5: Life activities				
Non-caregivers ^b				
Other caregivers	9.094 (4.423)	*	-0.861 (2.278)	NS
HIV-caregivers	2.232 (3.867)	NS	9.773 (2.751)	***
Constant	-22.357 (10.640)		-12.879 (6.665)	
R ²	8.4		9.4	
Model 6: Participation in society				
Non-caregivers ^b				
Other caregivers	1.166 (4.368)	NS	-3.459 (2.113)	NS
HIV-caregivers	0.279 (3.820)	NS	-1.366 (2.551)	NS
Constant	-6.996 (10.508)		-6.056 (6.181)	
R ²	6.9		2.2	
Model 7: Overall disability score				
Non-caregivers ^b				
Other caregivers	3.834 (2.437)	NS	1.471 (1.203)	NS
HIV-caregivers	2.221 (2.131)	NS	4.680 (1.453)	**
Constant	-12.196 (5.862)		-9.542 (3.520)	
R ²	16.5		13.6	

Note: Significance levels *** < 0.001; ** < 0.01; * < 0.05.

NS, not significant. Source: Authors analysis of Survey on Social, Health and Overall Wellbeing of Older People data, 2006/2007.

^aAge, education level, per capita income and wealth status added as control variables.

^bNon-caregivers taken as the reference category.

comparison of self-reported health among men and women who had provided care to someone with an AIDS-related illness with other caregivers and non-caregivers. Differential gender effect is envisaged due to variation in care-giving perception, attitude and roles between men and women.

The study found that women AIDS-caregivers did not differ significantly from other caregivers or non-caregivers in terms of the specific health domains, the overall disability score or in reporting having a severe health problem. On the contrary, men who were AIDS-caregivers were significantly more likely

Table 4. Logistic regression models on reporting a severe health problem for women and men.^a

	Women			Men		
	OR	CI		OR	CI	
Non-caregivers ^b	1.000			1.000		
Other caregivers	0.748	(0.29–1.88)	NS	3.512	(1.87–6.58)	***
HIV-caregivers	1.885	(0.81–4.39)	NS	7.983	(2.95–21.53)	***
Model χ^2	32.4			60.0		
Degrees of freedom	7			7		
Log likelihood	–328.5			–565.3		
R^2	7.1			5.8		

Note: Significance levels *** < 0.001; ** < 0.05.

NS, not significant. Source: Authors analysis of Survey on Social, Health and Overall Wellbeing of Older People data 2006/2007.

^aAge, education level, per capita income and wealth status added as control variables.

^bNon-caregivers taken as the reference category.

to report poorer health compared with other caregivers and non-caregivers.

A review of the literature to understand the gender differences observed in this study highlights the fact that men are known to downplay their health problems and hence under-report symptoms or distress especially in interview situations. Men are also socialised to be self-reliant, in control, courageous, and to portray self-confidence when faced with challenges or complex situations. Consequently, they are expected not to show feelings such as fear, anxiety, grief, or frustration and should be able to endure stress and bear pain and hence tackle care-giving tasks with control or stoically. Therefore, comparing women and men caregivers as opposed to caregivers and non-caregivers of the same gender, will point to worse health outcomes for women hence as an artefact of differential reporting (Benyamini, Blumstein, Lusky, & Modan, 2003; Idler, 2003; Spiers, Jagger, Clarke, & Arthur, 2003). In this regard, there is little evidence that men are less emotionally sensitive to care-giving and related burden or stress. The true level of health problems for men compared with women is therefore rarely measured (Brown, Chen, Mitchell, & Province, 2007; Mullan, 1998).

The other explanation of the differentials between men and women may arise from gender variation in gender-roles and coping strategies. Cultural expectations where men are expected to be in control and to show more endurance may lead to elevated levels of stress among men caregivers leading to poorer health outcomes (Kramer, 2002; Stoller, 2002). Similarly, unlike women, men do not utilise or seek informal support networks. This deters them from seeking support or discussing their problems or difficulties relating to care-giving (Ashley & Kleinpeter, 2002). Informal support has been found to have a mediating effect in caregiver burden and strain (Fuller-Jonap & Haley, 1995; Mullan, 1998).

Implications for HIV and AIDS health policies and programmes

Informal care-giving for PWA will continue to play a very crucial role in filling the void brought about by the inability of the formal health care systems to meet the needs of people with HIV and AIDS. The findings from this study have highlighted the role of older men as caregivers and the gender-variation that exists among caregivers in the extent to which care-giving is associated with poorer health outcomes. Older women have largely been portrayed as the face of HIV and AIDS care and support, with several studies pointing at them as disproportionately affected. There is however a need to recognize the role of older men as active and not passive caregivers at both the policy and programme level. Interventions targeted at people affected by HIV and AIDS should include older men. This may demand having gender-neutral or gender-specific interventions focusing on men and women.

The second implication of this study relates to the health care needs for AIDS-caregivers. While the current HIV and AIDS policy in Kenya seeks to improve the quality of life for people with HIV and AIDS through strengthening availability and access to treatment and care (National AIDS Control Council, 2005), the policy is silent on the health care needs for caregivers. One strategy would be to provide health care for a person with AIDS and their caregiver as dyads.

Limitations

The impact of care-giving manifests itself over a long period and the full extent of the effects can only be measured if individuals are followed up over a longer period of time. Other factors that act to mediate the effects of care-giving were not exhausted fully in the

paper although attempts were made to control for confounders during the analysis. The cross-sectional nature of the study cannot adequately measure causality between care-giving to a person with AIDS-related illness with health, so, the objective of this paper was to assess if there are any significant differences between the cases and the two comparison groups.

The study could not take into account heterogeneity among caregivers due to the small sample size of HIV caregivers. Another limitation is the inability to detect whether the comparison groups have not been affected in any way through spill-over effect thus potentially under-estimating or over-estimating if positively affected the impact on the comparison groups (Beegle & Weerd, 2007).

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