

Employment Changes among Chinese Family Caregivers of Long-Term Cancer Survivors

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Abstract

Background To describe the effect that providing cancer care to long-term cancer survivors has on the employment status of family caregivers (FCGs), and identify cancer-related characteristics that influence FCGs' employment status in the post-treatment phase in China.

Methods We surveyed 1155 cancer survivors (>1 year since completing treatment) from the cross-sectional study "China Survey of Experiences with Cancer". Participants reported changes in employment status of their FCGs. Descriptive statistics characterized the sample of survivors and FCGs' employment status. Separate multivariable logistic regression models were conducted to examine the association between participant cancer characteristics and changes in FCGs' employment status.

Results In the primary treatment phase, 45.6% of all FCGs reduced their working hours and 17.4% stopped working altogether. In the post-treatment phase, 25.2% of FCGs reduced working hours and 6.6% stopped working. A higher probability of change in employment status among FCGs was associated with the following cancer-related characteristics: late-stage diagnosis, chemotherapy treatment, comorbidity, and limited ability to perform physical and mental tasks.

Conclusions Cancer treatment and post-treatment demands may have a great number of impacts on the employment and economic productivity of Chinese FCGs. Interventions to assist them in maintaining employment are warranted across the whole survivorship trajectory.

Background

Data presented by GLOBOCAN 2018 indicated that there would be an estimated 18.1 million new cancer cases throughout the world in 2018, of whom approximately 24% reside in China [1]. This is largely due to the growth and ageing of China's population and changing risk factor patterns in the population. Accompanying the alarming rise in cancer incidence in China over the past few decades, the survival rate of cancer has also risen significantly due to efforts aimed at early cancer detection as well as advances in treatment [2, 3]. The National Central Cancer Registry of China (NCCR) reported that among all cancer types in China, the age-standardized 5-year survival rate rose from 30.9% during 2003-2005 to 40.5% during 2012-2015 [4]. As a result, the need to support cancer survivors has become more important. As a chronic disease, after the preliminary treatment of cancer has been accomplished, the illness trajectory of most cancers can continue to undermine the well-being of cancer survivors [5]. Some of the lasting outcomes of cancer include fear of disease recurrence, facing difficulties adjusting and adapting to one's new self and relationships with others, and feeling unprepared for the survivorship period and eager for external assistance [6]. Thus, as a type of family resource, during the period of post-treatment after returning to the community, follow-up care from informal caregivers is valuable in helping meet the needs of the cancer patient. Generally speaking, individuals (e.g. adult children, spouses, parents, and siblings) who offer domestic care are called "family caregivers (FCGs)", and they are required to spend several months or even years' worth of time and effort without compensation or without concerns about their physical, emotional, social or economic well-being [7].

Currently, extensive research has shown that FCGs of cancer survivors can generate a positive influence by reducing the societal burden of treatment, reducing expenditures for the national healthcare system, and contributing to the further rehabilitation of cancer patients [8-10]. However, with these benefits may come risks or even harm. A majority of FCGs face stressors from many different directions [11-14]. A great number of FCGs may have to pay high medical expenses for their sick family member, lose wages or savings, provide time-consuming care without professional direction or support, experience overwhelming mental pressure, and/or suffer from deteriorations in their own quality of life [15-17]. Fletcher et al. stated that among 60 female FCGs in their study, 15.0% experienced physical aches and pains, 36.7% sleep paucity, 33.3% morning fatigue, and 30.0% evening fatigue [18]. A previous study suggested that more than 80% of FCGs need to assist other family members in processing complex emotions [19]. Another study showed that about 74% of FCGs suffered malign economic or social changes since the patients' diagnosis [13]. Thus, cancer survivorship could generate a substantial effect on not only the long-term health and quality of life of the patients themselves, but also on their FCGs. In such a case, coupled with a paucity of literature on this group during the survivorship period, solid research that emphasizes the standpoint of FCGs awaits exploration, particularly with regard to both the declining harm to FCGs and the patients they serve. Specifically, for the subgroup of FCGs who are employed, compared with full-time caregivers, multiple demands from caregiving and work result in the disruption of daily caregiving and occupational affairs without support and adequate resources, which ultimately subject them to extra pressures. Lai found that compared with non-caregiving peers, a lower working productivity was observed in the FCGs group, because they were more exhausted, required more days off from work, and left the office earlier to support

their family members in post-treatment [20]. Additionally, giving up career advancements and opportunities for promotion were also frequently found within this subgroup; some would even like to leave their jobs to concentrate fully on their caregiving role [20]. Efforts to investigate this subgroup of FCGs have been pursued in Western countries. For instance, due to the liability of care and a shortage of extra time, more than 77% of FCGs in a study missed work in the terminal period of cancer care [21]. A quarter of cancer FCGs modified their employment status because of providing care [22]. Another study estimated that 22% of cancer FCGs decided to reduce their working time or quit their jobs [23].

In China, researchers have started to pay attention to the field of FCGs as well. For example, researchers have begun to investigate several factors connected with caregiver burdens, such as patient age, type of health insurance, and social assistance [24]. Information conveyed between patients and their FCGs displayed that these interactions facilitate mutual understanding about the patient and the caregiver's needs [25]. Offering informal care to family members might drastically reduce the quality of life of FCGs, especially their mental health [26]. Also, results from a survey which was conducted among Chinese Canadians showed that the Chinese culture did highlight filial obligation as an excellent tradition, but unfortunately, this kind of caregiving obligation was not without any other risks, the employment of FCGs could be regarded as a predictor of economic costs in the family [27]. To our knowledge, however, Chinese scholars have not pursued an in-depth understanding of employed FCGs of cancer survivors. Employed FCGs have neither been supported by the national health system nor funded by non-profit institutions, both of which play small, but important, roles in post-treatment and the support of cancer survivors. In the first year after cancer diagnosis, even after attaining medical insurance reimbursement, the financial burden for lung cancer for a family amounted to nearly 107% of the whole annual household income in China [28]. Additionally, owing to China's cultural context, most Chinese cancer survivors mainly rely on their family members for daily life needs, rather than hiring professionals [24, 25, 29, 30]. Notably, much research is needed to assist policy makers and healthcare providers in developing interventions, directives and social care programs targeted at reducing the burden on FCGs.

Thus, the main aims of this study are to describe the effect of that providing cancer care to long-term cancer survivors has on the employment status of family caregivers, and then identify the cancer-related characteristics that influence FCGs' employment status in the post-treatment phase in China.

Methods

Sampling

We used the Cancer Supplement of the Medical Expenditure Panel Survey (MEPS) as a reference to design the "Your Experiences with Cancer in China" survey for cancer patients identified in the cancer registry system [31]. The final in-person survey was conducted between March 2015 and March 2016. A stratified random sampling framework was used for this study. Eight county-level units were purposively chosen as representative of the population of Shandong province in terms of demographic context and socioeconomic development. The sample was stratified by rural versus urban status. The final sample consisted of cancer survivors from 5 rural counties and 3 urban districts. Counties and districts are at the same level in the Chinese administrative division system. Patients in rural counties are covered for the most part by rural resident insurance, and the majority of survivors in urban districts enjoy 1 of 2 urban health insurance schemes. In each county/district, cancer survivors diagnosed with the most common cancers (breast, lung, colorectal, and gastric) during the study period were randomly chosen from the central cancer registry file. Investigators excluded patients who were diagnosed with multiple cancers. The survey assigned 1600 cancer cases to interviewers. Eligible participants: 1) were previously diagnosed with the most common cancers (lung, stomach, colorectal, female breast) between 2011 and 2014, 2) were at least 18 years old at the time of cancer diagnosis, 3) had completed primary cancer treatments (surgery, chemotherapy, and radiation therapy) more than 1 year ago, and 4) had been cared by FCGs who were employed before the patients were diagnosed. A total of 1155 cancer survivors were ultimately analyzed in this study.

Study Measures

At the beginning of the survey, all patients received an explanation about the purpose of the study. Individuals were asked to sign consent forms if they were willing to participate in the survey. After acquiring written consent forms, participants were interviewed face-to-face by trained investigators at their homes. Demographic characteristics of the participants included residence area, age, gender, marital status, educational level, and annual household income. Cancer-related characteristics of participants included cancer site (breast/lung/stomach/colorectal), stage at diagnosis (0-I/II/III-IV), type of treatment (chemotherapy/surgery/radiation therapy), comorbidity (yes/no), limited ability to perform physical tasks (yes/no), limited ability to perform mental tasks (yes/no), and duration

of disease since diagnosis (2-3years/4-5years). The indicator “comorbidity” was identified as “yes” if any ordinary chronic disease (e.g. diabetes, cardiovascular diseases, respiratory diseases) was diagnosed.

In order to evaluate employment changes in FCGs, participating cancer survivors were asked two questions: (a) “Throughout your cancer treatment, did any of your caregivers shorten their working hours because of your cancer, its treatment or the lasting effects of the treatment?” (b) “In the post-treatment phase, did any of your caregivers shorten their working hours because of your cancer, its treatment or the lasting effects of the treatment?” The results were categorized: a) Increased working hours; b) Kept the regular working hours; c) Reduced working hours by less than half; d) Reduced working hours by half; e) Reduced working hours by more than half; f) Stopped working; g) Not applicable (retired or unemployed when they were first diagnosed). In this study, we defined those patients who had completed primary treatment at least one year ago as “in post-treatment phase”, and those who had completed primary treatment within one year or who were still receiving chemotherapy, radiation, and/or surgery for their cancer or undergoing cancer treatment in hospital were categorized into the group “in primary treatment phase”. Approval from the Ethics Committee of the School of Public Health at Shandong University (NO.20140201) was obtained.

Statistical analyses

In the final analysis, item response categories “a”, “b” and “f” were treated as separate groups, while “c”, “d” and “e” were combined into one group as “Reduced working hours” for a total of four groups. Changes in employment that were not due to FCG requirements were excluded from the above four groups in this study. Descriptive analyses were performed to describe the participants’ characteristics and the employment changes among FCGs at two stages (in primary treatment/ post-treatment phase), separately. A chi-squared test was conducted to assess the possible association between each independent variable and employment changes among FCGs in the post-treatment phase. “Reduced working hours” and “Stopped working” were classified as employment changes = “Yes: FCG took time off from working (FCGs)”; “Kept the regular working hours” was classified as employment changes = “No: FCG did not take time off from working (FCGs).” After controlling for all patient demographic characteristics, separate multivariable logistic regression models were then used to examine the factors associated with employment changes among FCGs. The multivariable model for cancer site was adjusted for residence area, age, marital status, annual household income, and educational level. All other multivariate models were adjusted for residence area, age, gender, marital status, annual household income, and educational level. In this study, a two-tailed probability value of below 0.05 was considered statistically significant. All analyses were conducted via the SPSS 21.0 statistical package (SPSS Inc., Chicago, IL, USA).

Results

Description of characteristics of cancer survivors

As presented in Table 1, 1155 survivors were ultimately included in this study. Only a few (6.8%) of the participants were recorded with stage III-IV cancer. Types of treatment included chemotherapy (68.7%), radiation therapy (11.6%), and surgery (88.9%). 26.9% of participants were accompanied by chronic diseases. In the post-treatment phase, over half (55.3%) of participants in the survey reported that their ability to perform physical tasks was limited, and approximately one-third (31.3%) of participants reported their ability to perform mental tasks was limited.

Employment changes experienced by FCGs

As presented in Figure 1, in the primary treatment phase, nearly half of FCGs (45.6 %) reduced their working hours, and 17.4% of FCGs even stopped working due to care provision. In contrast, only a small percentage (3.0%) increased their working hours. In the post-treatment phase, nearly a quarter (25.2%) reduced their working hours due to care provision, and there was still a small percentage (6.6%) of FCGs who stopped working. There was a statistically significant difference between the employment status of FCGs in the primary treatment phase and in the post-treatment phase ($P < 0.01$).

In the post-treatment phase, among demographic variables, different residence areas ($P < 0.001$), gender ($P = 0.014$), marital status ($P = 0.014$), educational level ($P < 0.001$), and annual household income ($P < 0.001$) registered as statistically significant, revealing their impact on the employment status of FCGs. As for cancer-related characteristics, comorbidity ($P = 0.004$), chemotherapy treatment ($P = 0.001$), limited ability to perform physical tasks ($P < 0.001$), limited ability to perform mental tasks ($P = 0.025$), and duration of disease since diagnosis ($P = 0.001$) were statistically significant.

As presented in Table 2, in the analysis which controlled for all patient demographic characteristics, for survivors of stage II cancer (OR=1.481; 95CI%: 1.083, 2.024), the probability that their FCGs' employment status would change was higher than that of the comparison group. For survivors who had already undergone chemotherapy treatment (OR=1.638; 95CI%: 1.202, 2.232) and were accompanied by another chronic disease (OR =1.593; 95CI%: 1.148, 2.210), their FCGs were more likely to have made employment changes. In addition, for survivors whose ability to perform physical tasks (OR =1.742, 95%CI: 3.154, 10.339) and mental tasks (OR=1.513, 95CI%: 1.100, 2.081) was limited, their FCGs also were more likely to have changed their employment status.

Discussion

The study presents new data showing that the FCGs of cancer survivors in China made a variety of employment changes in assuming their caregiving responsibilities. In this study, 24.6% of FCGs reduced their working hours and 6.4% of FCGs stopped working to provide care (in the post treatment phase). Our results match de Moor et al.'s study in which approximately 25% of survivors reported their caregivers making employment changes [22]. Clearly, a notable number of FCGs of long-term survivors both nationwide and worldwide have experienced significant employment losses, and as such, efforts concentrating on the study of their employment changes are strongly recommended.

Our study found that patients who suffered chronic diseases were more likely to influence the employment status of their FCGs. Previous research findings have also recorded the negative influences that survivors with multiple chronic diseases have on the health-related quality of life (HRQoL) of their caregivers. For example, Kurtz et al. reported that 73.4% of cancer patients in their study who had suffered from comorbidity had a negative impact on the HRQoL of their caregivers [32]. Our study adds to the literature by confirming that accompanying chronic disease is associated with a higher probability of employment change among FCGs. Cancer survivors with chronic disease could bring incremental burdens, such as life disability, household productivity loss, and extra days confined to bed due to poor health, which might affect FCGs' working hours greatly.

In our study, patients treated with chemotherapy were more likely to adversely affect the employment status of their caregivers. This is consistent with several existing studies [22, 33], which found that for FCGs whose patients were treated with chemotherapy, the probability of altered employment status was higher than those not treated with chemotherapy. Compared to other therapy methods, chemotherapy might be viewed as a catastrophe for both patients themselves and their families due to the long duration and recovery period, combined with more burdensome symptoms and poor prognosis. In traditional Chinese culture, caregivers usually accompany patients over the whole course of hospitalization, and stay bedside until their loved ones are discharged. Facing substantial care tasks, they must modify their work schedule. However, in a US study, although chemotherapy treatment was associated with a decline in caregivers' involvement in their own daily routines, it was not a significant predictor of the decline [13]. The discrepancy might be explained by the difference in treatment settings and approach. In the US, most cancer patients undergo chemotherapy in an outpatient clinic, which can be completed within 3 to 4 hours each time [34]. Although some Chinese hospitals can provide chemotherapy treatment in an outpatient clinic as well, the social health insurance system in China is oriented toward inpatient expenditures rather than outpatient expenditures in terms of reimbursement rate and ceiling amount. As a result, Chinese cancer patients are likely to receive chemotherapy treatment during hospitalization [35]. Whether chemotherapy is a significant risk factor for FCGs deserves further study and policy debate on how to best support the economic needs of FCGs while they are caring for cancer survivors.

FCGs of patients with limited ability to perform physical or mental tasks were also more likely to experience employment changes in our study. Although our findings are inconsistent with that from Sherwood et al., who indicated that FCGs' employment condition was not influenced by the patient's ability, our results are in agreement with other previous studies [22, 36]. Loss of ability to perform tasks is important because it is an indicator of poor physical and mental health. If a cancer survivor's household work and/or income from employment was the main source of household support, once he/she is diagnosed with cancer and receives treatment, the tasks that the survivor previously undertook would have to be done by their caregiver. To maintain the normalcy of family life, FCGs may be obligated to dedicate a portion of their working hours to providing family assistance.

Finally, our study did not concur with previous studies in which survivors diagnosed with advanced-stage cancers tended to place the heaviest burden on the regular schedule of FCGs. For example, cancer patients who had been diagnosed at a later stage would require more caregiving hours from FCGs [37]. The discrepancy in our finding may derive from the fact that this study was a household survey of cancer survivors, of whom survivors at a later stage accounted for only a small proportion. This study may have been subject to "survivor bias" as healthier patients are more likely to be discharged to return home.

This study assessed the extent of FCGs' employment changes which resulted from caregiving, and then identified caregivers who are at high risk for making employment changes. Going beyond our study, many other high-risk factors might play a critical role in the employment changes of FCGs as well, such as the existing labor law on governing "sick leave" in China, which does not provide any legitimate job-protection for FCGs [38], and the smaller family size in China [25]. In such a situation, FCGs will ultimately become the "hidden victims", and therefore it should be a high priority to identify and focus further intervention efforts on these individuals.

Several limitations of this study need to be mentioned. Firstly, information on the demographic characteristics and the detailed employment level (e.g. part-time versus the full-time) of FCGs was lacking, prohibiting a robust analysis of the associations between each occupation and subsequent outcomes. Future investigations that focus on the FCGs' side might uncover fresh insights into variables related to their employment changes. Secondly, the reporting bias of investigators in reviewing the FCGs' employment changes is inevitable in our study; meanwhile, patients may view the employment changes that their FCGs had suffered in a narrow or broad sense, which might bring about an under- or over- estimation. Future work is expected to involve more objective indicators to ensure accuracy and validity.

Conclusion

Most Chinese family cancer caregivers commonly overlook their own affairs, focusing more, if not absolutely, on their sick loved ones in order to give full-time care, which in turn may lead to serious negative implications, such as a decrease in household income, and furthermore lead to heavy family burden. Assessment of associated factors that affect FCGs' employment conditions might help to identify individuals in need of greater support. Tailored interventions and assistance should therefore be accordingly planned to help them deal with the dilemma of care demands and employment affairs.

Abbreviations

FCGs: Family caregivers

HRQoL: Health-related quality of life

Declarations

Ethics approval and consent to participate

All procedures performed in this study are in accordance with ethical standards of the Institutional Review Board at the School of Public Health at Shandong University (NO.20140201), and with the Declaration of Helsinki. Written informed consent was obtained from all participants before data collection.

Consent for publication

Consents for publication were obtained from all participants.

Availability of data and materials

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests

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Authors' contributions

SL drafted the manuscript and contributed the interpretation of results. MS conducted the statistical analyses and gave the results. NY contributed to the design of the analysis plan and critically read and commented on manuscript drafts. NZ contributed to the investigation and data curation. JW and RA were responsible for supervision and administration of the project. XS was accountable for all aspects in ensuring the quality of questions related to the accuracy or integrity of any part of the work. All authors read and approved the final manuscript.

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Tables

Table 1 Characteristics of cancer survivors (N=1155)

Characteristics	N (%)
Residence area	
Urban	379(32.8)
Rural	776(67.2)
Age group(years)	
≤40	45(3.9)
40-55	299(25.9)
56-65	384(33.2)
>65	427(37.0)
Gender	
Male	496(42.9)
Female	659(57.1)
Marital status	
Married	1037(89.8)
Others	118(10.2)
Educational level	
Uneducated	185(16.0)
Elementary school	403(34.9)
Middle school	377(32.6)
High school and above	190(16.5)
Annual household income [†] Chinese Yuan	
<5,000	182(15.8)
5,000-20,000	417(36.1)
20,000-50,000	376(32.6)
>50 000	172(14.9)
Missing	8(0.7)
Cancer site	
Breast	406(35.2)
Lung	163(14.1)
Stomach	284(24.6)
Colorectal	302(26.1)
Stage at diagnosis	
0- I	497(43.0)
II	405(35.1)
III-IV	78(6.8)
Missing	175(15.2)
Type of treatment [‡]	
Chemotherapy	794(68.7)
Surgery	1027(88.9)
Radiation therapy	134(11.6)
Comorbidity	
Yes	311(26.9)
No	813(70.4)
Missing	31(2.7)
Limited ability to perform physical tasks	
Yes	639(55.3)
No	123(10.6)
Not applicable [§]	393(34.0)
Limited ability to perform mental tasks	
Yes	362(31.3)
No	425(36.8)
Not applicable [§]	368(31.9)
Duration of disease since diagnosis	
2-3 years	745(64.5)
4-5 years	410(35.5)

[†] 10,000 Chinese Yuan ≈1,541 US dollars as of December 31, 2015;

[‡] Categories are not mutually exclusive because most patients received a combination of treatments[□]

[§] Participants who were retired or unemployed by the time they were diagnosed with cancer can be identified as “Not applicable”.

Table 2 Associated factors of employment changes among FCGs from separate multivariable logistic regression analyses

	Odd Ratio, OR									
	Model 1	Model 2	Model 3 [‡]	Model 4	Model 5	Model 6	Model 7	Model 8	Model 9	Model 10
Age at time of survey[†]	0.992	0.997	0.998	0.995	0.995	0.992	0.993	0.993	1.003	0.993
Residence area										
Urban	Ref									
Rural	2.191***	2.136***	2.314***	2.534***	2.082***	2.259***	2.223***	2.078***	1.965**	2.252***
Gender										
Male	Ref									
Female	0.720*	0.704*		0.730*	0.701*	0.722*	0.718*	0.730*	0.821	0.697*
Marital status										
Others	Ref									
Married	2.051**	2.176**	2.098**	1.860*	1.994**	2.105**	2.049**	2.052**	1.862	2.229*
Education										
Uneducated	Ref									
Elementary school	1.204	1.148	1.276	1.093	1.204	1.220	1.207	1.240	1.119	1.230
Middle school	0.802	0.766	0.896	0.751	0.786	0.810	0.803	0.822	0.626	0.695
High school and above	0.385**	0.351*	0.433**	0.363**	0.384**	0.388**	0.391**	0.395**	0.388*	0.306**
Yearly household income, Chinese Yuan										
<5,000 CNY	Ref									
5,000-19,999 CNY	0.685	0.675	0.683	0.778	0.685	0.693	0.681	0.682	0.776	0.728
20,000-50,000 CNY	0.742	0.744	0.728	0.873	0.692	0.748	0.741	0.734	0.976	0.927
>50,000 CNY	0.578	0.600	0.569	0.584	0.536*	0.593	0.575	0.573	0.976	0.921
Comorbidity										
0		Ref								
≥1		1.593**								
Cancer site										
Colorectal			Ref							
Female breast			1.021							
Lung			0.933							
Stomach			0.992							
Cancer stage at diagnosis										
0-I				Ref						
I				1.481*						
I-II				1.394						
Chemotherapy										
No					Ref					
Yes					1.638**					
Surgery										
No						Ref				
Yes						0.736				
Radiation therapy										
No							Ref			
Yes							1.187			
Duration of disease since diagnosis										
2-3 years								Ref		
4-5 years								1.249		
Limited ability to perform physical tasks										
No									Ref	
Yes									5.710***	
Limited ability to perform mental tasks										
No										Ref
Yes										1.513*

[†] Age was entered as a continuous variable in the regression model.

‡ The model 3 for cancer site adjusted for residence area, age, marital status, annual household income, and educational level. Models 2, 4-10 adjusted for residence area, age, gender, marital status, annual household income, and educational level.

***, **, * indicates $P < 0.001$, $P < 0.01$; $P < 0.05$, respectively.

Figures

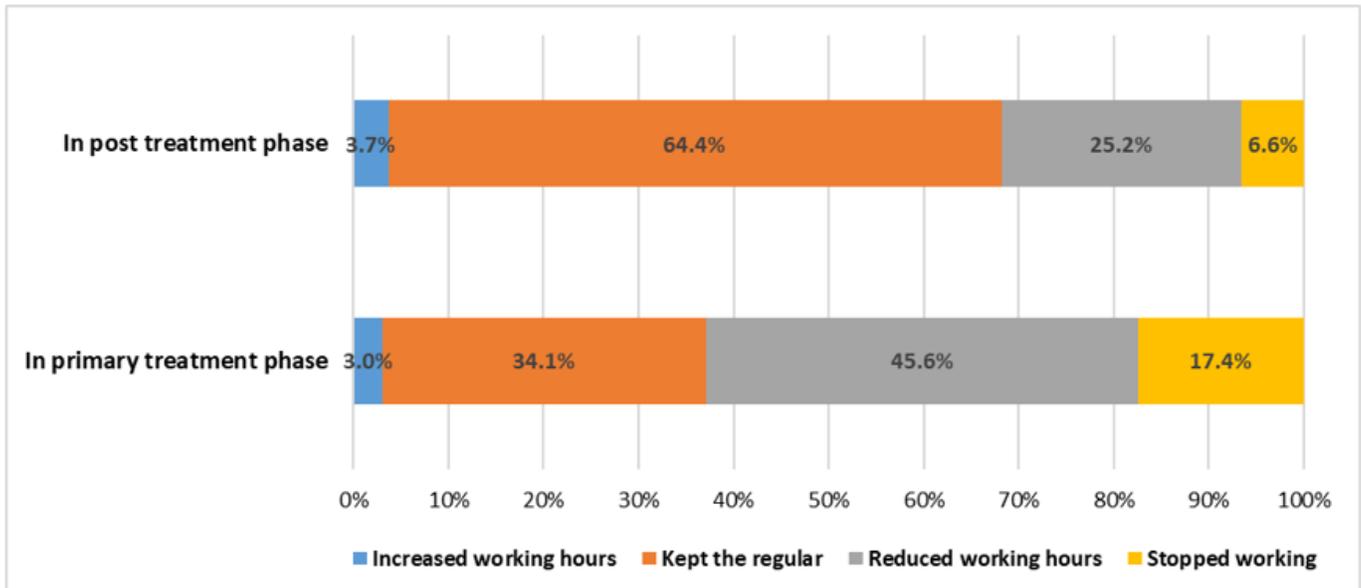


Figure 1

Proportions of different types of employment changes among FCGs