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Primary Care Physician Perspectives on Caring for Adult Survivors of Hematologic Malignancies and Hematopoietic Cell Transplantation

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Abstract

Background: Primary care physicians (PCPs) may face barriers to caring for hematologic malignancy and hematopoietic cell transplantation (HCT) survivors.

Methods: A web-based survey consisting of 40 questions and 2 case scenarios was administered to 302 PCPs at two large integrated healthcare systems. The questionnaire assessed perceived barriers to delivery of care to hematologic malignancy/HCT survivors, resources available to care for cancer survivors, practices for care coordination with hematologist-oncologists, and preferred models of care delivery.

Results: Overall response rate was 30% (N=86). PCPs reported several barriers such as lack of resources to facilitate care (69%), lack of awareness of screening/prevention guidelines (55%) and psychosocial needs of survivors (65%), inadequate time (65%), and patient preference to follow up with their oncologists (66%). They expressed confidence in caring for general medical issues (84%) and general cancer screening (73%), but preferred oncologists manage cancer related medical issues (42%), screen for cancer recurrence (52%) and secondary cancers (55%). In multivariable analysis, PCPs who had previously cared for larger number of hematologic malignancy/HCT survivors and those further out since graduation from medical school had greater confidence in managing cancer related medical issues.

Conclusions: PCPs report several barriers in providing care to hematologic malignancy/HCT survivors. Clinical experience with this patient population is associated with greater confidence in providing survivorship care. Several barriers identified by PCPs in providing survivorship care to

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hematologic malignancy/HCT survivors are potentially addressable by education, clinical decision support tools and guidelines, enhancing clinical experience, and care coordination with hematologist-oncologists.

MICRO-ABSTRACT

In a survey of primary care physicians at two large integrated healthcare systems, several barriers to providing care to hematologic malignancy/hematopoietic cell transplant survivors were identified, several of which are potentially addressable by education, enhancing clinical experience, and care coordination with hematologist-oncologists. Clinical experience with this patient population is associated with greater confidence in providing survivorship care.

Keywords

Cancer survivor; Hematologic malignancy; Hematopoietic cell transplantation; Late complications; Care delivery; Models of care; Primary care physicians

1. INTRODUCTION

Advances in treatment for hematologic malignancies and hematopoietic cell transplantation (HCT) has led to improved survival and increasing number of adult long-term survivors of diseases such as acute and chronic leukemia, myelodysplastic syndromes, lymphoma and multiple myeloma^{1–7}. These survivors are at risk for long-term complications including late infections, secondary cancers, psychosocial stress, graft-versus-host disease and are hence considered moderate to high risk groups in the risk stratified approach to survivorship⁸. With the exception of Hodgkin lymphoma, long-term mortality and late effects have not been systematically studied in survivors of hematologic malignancies⁹. However, extensive research on HCT survivors shows that their relative mortality rates continue to remain higher than expected compared to their general population peers through at least 15 years after transplantation^{10–12}. Excess mortality is primarily driven by late complications and guidelines recommend lifelong follow up with regular evaluations for their screening and prevention^{9, 13, 14}.

Cancer patients who are in remission long-term after their treatment frequently receive healthcare through their primary care physicians (PCPs) and are less likely to be under the care of cancer centers and hematologist-oncologists^{15, 16, 17}. However, several PCP barriers to providing survivorship care have been identified, such as lack of training and uncertainty about general preventive care responsibilities^{18–20}. These barriers may be accentuated and different for hematologic malignancy and HCT survivors, given the rarity of their diagnoses, the highly-specialized nature of treatments that these patients receive, and their associated complications. With this background, we conducted a survey of PCPs at two institutions to identify the knowledge gaps and perceived barriers in the management of survivorship issues in this patient population, and to identify their current practices, utilization of available resources and coordination of care with specialists.

2. METHODS

2.1 Study Sites

A cross-sectional survey was administered to Internal Medicine and Family Practice physicians caring for adult patients and practicing through the Cleveland Clinic in Cleveland, Ohio and the Mayo Clinic in Scottsdale, Arizona. Both institutions have a similar model with a main tertiary care academic medical center and satellite clinics in the regional area, with PCPs employed in an integrated health system. Care for hematologic malignancies and HCT is mainly provided through hematologist-oncologists at cancer centers located at their main tertiary care hospitals. Most long-term survivorship care for hematologic malignancies and HCT survivors is provided through hematologist-oncologists with varying degree of involvement by patient's PCPs. Patients are typically treated at the main campus location, especially allogeneic HCT recipients who are also required to stay locally through at least day +100 after transplantation. The frequency of subsequent post-transplant follow up varies based on patient needs, underlying diagnosis and presence of post-transplant complications, although allogeneic HCT recipients are followed for life. Routine interactions between the two groups of physicians varies, depends on the clinical status of the patient, and is usually focused around sharing of patient notes and information through electronic medical record at each site.

2.2 Survey Development

We adapted a previously published survey instrument that assessed physician knowledge, beliefs and practices regarding the care of breast and colon cancer survivors for our study¹⁸. Questions specific for hematologic malignancy and HCT survivors were added to the questionnaire. Broadly, the survey addressed PCP knowledge of long-term complications and recommended preventive follow-up care for survivors of hematological malignancies and HCT, their perceived barriers and limitations to delivery of care to this patient population, resources needed and currently available to provide care to cancer survivors in general, their current practice for care coordination with hematology-oncology providers for cancer survivors in general, and their preferred models of care delivery for hematologic malignancy and HCT survivors. Additionally, case vignettes were included to understand the willingness of PCPs to provide routine medical care for patients with varying complexity of survivorship care needs.

The survey instrument was piloted with 5 PCPs at the Cleveland Clinic to address any redundancy in its content, to obtain feedback on case vignettes, and to provide an estimate of the time for completion. The final instrument consisted of 40 questions. Responses regarding perceptions and barriers were organized in an ordinal scale and were "Never", "Rarely", "Often" and "Always". Questions about resource utilization were categorized as "Not helpful", "Somewhat helpful" and "Very helpful". Based on pilot study feedback, two case scenarios were chosen for inclusion in the final survey and represented patient situations that were most likely to be seen independently by PCPs and required minimal active ongoing care by hematologist-oncologists. First scenario represented a 40-year old female, three years after completion of therapy for acute myeloid leukemia (AML) with an uncomplicated treatment course and asked respondents to describe their confidence in independently

providing care for general medical issues, cancer-related medical issues, screening for cancer recurrence and secondary cancers. Respondents could answer on a Likert scale as “Not at all confident”, “Somewhat confident” and “Very confident”. The second scenario represented an identical patient, with the exception that the patient had also received an allogeneic HLA-identical sibling donor transplant but had no post-transplant complications.

Practice information gathered from respondents included number of hematologic malignancy and HCT survivors seen in their practice within the past 5 years, primary specialty, site of practice, present involvement in teaching medical students or residents, number of patients seen in a typical week, and year of medical school graduation.

2.3 Survey Administration

The final survey was administered as a web-based survey using REDCap at both institutions and took an estimated 10–15 minutes to complete. An initial email invite with a link to the survey was sent to PCPs on their institutional email accounts and was followed by two reminders 2 weeks apart. Respondents were instructed to consider patients with hematologic malignancies and HCT recipients (acute and chronic leukemia, myelodysplastic syndrome, lymphoma, and myeloma) who had completed active treatments, were in remission, and did not require intensive monitoring by hematologist-oncologist for at least one year or more following completion of therapy. Twenty respondents were randomly chosen to receive a Visa gift card of \$50 at the Cleveland Clinic and 15 respondents were randomly chosen to receive a Visa gift card of \$25 at the Mayo Clinic. The study was conducted under guidance of Institutional Review Boards of both participating institutions.

2.4 Statistical Analysis

Data from REDCap were exported into SAS for analysis. For analysis, responses of “Never” and “Rarely” were combined as one category and “Often” and “Always” were combined as a second category. For questions inquiring about resources, no one answered “Not helpful” and the analysis considered “Somewhat helpful” versus “Very helpful”. Confidence questions for case vignettes were analyzed as “Not confident” versus “Somewhat confident” versus “Very confident”. For ordinal categorical PCP characteristics (number of survivors cared for, number of patients seen, years since graduation), associations with binary responses were analyzed with Cochran Armitage trend test and associations with ordinal responses were analyzed with Cochran-Mantel-Haenzel correlation test; both assess trends across levels of PCP characteristics. For binary categorical PCP characteristics (primary specialty, practice site, teaching), associations with binary responses were analyzed with Chi-square test and associations with ordinal responses were analyzed with Cochran-Mantel-Haenzel mean score test. We also performed an analysis to evaluate the association of PCP characteristics with their confidence in managing various scenarios in the two case vignettes. First, ordinal logistic regression was done for the four questions associated with each of the two vignettes. Then stepwise logistic regression analysis with a variable entry criterion of $p < 0.10$ and a variable retention criterion of $p < 0.05$ was used to identify multivariable prognostic factors. Results are summarized as odds ratio (OR), 95% confidence interval (CI), and p-value.

3. RESULTS

3.1 Physician Characteristics

A total of 302 PCPs were invited to participate in the survey, including 256 employed at the Cleveland Clinic and 37 at Mayo Clinic, Arizona. There were 59 respondents from Cleveland Clinic and 27 from Mayo Clinic with an overall response rate of 29%. The practice patterns of the 86 respondents are outlined in table 1.

3.2 Responses to domains assessed by survey

Among respondents, 54% indicated that they “often/always” received comprehensive treatment summary and 75% “often/always” received periodic updates from the hematologist-oncologist. Overall, 63% of the PCPs had no difficulty transferring patient care responsibilities with the hematologist-oncologist and only 45% discussed screening for cancer recurrence, secondary cancers or late effects with the patient.

PCPs reported several barriers in providing care for cancer survivors. The most common physician related barrier was the lack of resources to facilitate survivor care (69%) and the most common patient related barrier was the lack of clarity by patients on who to approach for care if health issues arise (77%). Other barriers noted are elucidated in fig. 1a and fig. 1b.

PCPs preference for providing care for hematologic malignancy and HCT survivors regarding general medical and cancer-related medical issues, psychosocial and fertility issues, screening for cancer recurrence, general and secondary cancers either independently or by sharing responsibility with the hematologist-oncologist are depicted in fig. 1c. Resources reported to be “very helpful” for providing survivor care included survivor care plan (86%), treatment summary (86%), structured follow-up plan (87%) and EMR implemented guidelines (78%). Fig. 2a and 2b summarize self-rated confidence responses of PCPs to the questions in the AML chemotherapy only and HCT case vignettes.

3.3 Associations between responses and PCP characteristics

PCPs who had cared for a greater number of hematologic malignancy/HCT survivors in the past five years were more likely to report that they “often/always” received a comprehensive treatment summary, received periodic updates, and discussed screening/late effects with the patient. Furthermore, they were more likely to prefer to be involved with screening for cancer recurrence, general and secondary cancers, and management of fertility issues. Likewise, there was higher level of confidence in managing cancer-related medical issues in chemotherapy only case scenario and in managing general medical issues or cancer-related medical issues in HCT case scenario. There was also increased confidence in screening for cancer recurrence and secondary cancers in both cases (Table 2).

As number of survivors cared for in the past five years increased, there were decreases in the proportion of PCP’s who “often/always” had issues with inadequate resources to facilitate survivor care or inadequate communication with the hematologist-oncologist. On a related note, as number of patients seen in a week increased, there were decreases in the proportion

of respondents who “often/always” had difficulty transferring patient care responsibilities and who lack awareness of screening/prevention guidelines.

As the years since graduation from medical school increased, respondents reported higher level of confidence in managing cancer-related medical issues and screening for cancer recurrence in both case scenarios. Additionally, as years since graduation increased there were decreases in the proportion of PCPs who “often/always” reported lack of awareness of clinical/psychosocial needs of survivors and of screening/prevention guidelines.

No associations were identified for primary specialty and practice site. However, a higher percentage of responders with teaching responsibilities preferred to handle general medical issues, general cancer screening and management of psychosocial issues. They were also more confident in chemotherapy only case scenario in dealing with general medical issues that may or may not be related to cancer.

In multivariable analysis evaluating the association of PCP characteristics and confidence in managing survivorship issues for the AML chemotherapy only case scenario (Table 3), PCPs who had cared for a greater number of hematologic malignancy/HCT survivors in the past five years were more confident in managing cancer-related medical issues, screening for cancer recurrence and secondary cancers. Likewise, there was increased confidence in handling general medical issues by PCPs with teaching responsibilities and cancer-related medical issues, screening for cancer recurrence by PCPs with increased time since graduation from medical school.

For the HCT case scenario, more years since graduation from medical school was associated with greater confidence in treating cancer-related medical issues and screening for cancer recurrence. Furthermore, PCPs who had cared for a greater number of survivors in the past five years were more confident in managing general medical issues, cancer-related medical issues and screening for secondary cancers.

4. DISCUSSION

PCPs are integral to providing comprehensive multidisciplinary survivorship care to cancer patients. Our study has identified several barriers that PCPs face in providing care to hematologic malignancy and HCT survivors. We also identify opportunities for facilitating survivor care through PCPs and areas that may be more appropriate for collaborative care with hematologist-oncologists or other specialists.

In comparison to solid tumors, hematologic cancers are relatively rare and heterogeneous, and patients receive a myriad of treatments and exposures. Only a small proportion of patients with hematologic malignancies go on to receive HCT, which makes this survivor population even smaller. Hence, our survey findings are not surprising given this context where PCPs have a low likelihood of caring for hematologic malignancy and HCT survivors in their practice. The significant findings among others were that about half of PCPs in our study were not aware of the screening guidelines, and psychosocial needs of all cancer survivors and half of them did not discuss screening/late effects with the patient. Overall, this and other observations from our study suggests a need for improved physician education

and training in survivorship care in our patient population of interest of hematologic malignancy and HCT survivors. Such training could occur through participation in specialized programs, continuing medical education conferences and workshops²¹.

A majority also reported that they lacked the resources including time to provide care. A notable proportion did not face challenges like difficulty transferring care responsibility, insufficient communication with the oncologist and inadequate reimbursement. This is substantially different from earlier studies which report poor care coordination between the oncologist and the PCP²²²³. A plausible explanation is the practice settings of an integrated cancer center in which the study was conducted, where PCPs and hematologist-oncologists are more likely to be familiar with each other and possibly face less barriers in communicating. PCPs concerns of lack of clarity by the patients on who to approach for care if health issues arise and preference to follow up with their oncologist only suggest a need for patient education as well.

PCPs were willing to assume exclusive responsibility in handling general medical issues that may or may not be related to cancer and general cancer screening for hematologic malignancy and HCT survivors. The finding that the resources that have been “very helpful” for this purpose are survivorship care plan, treatment summary, structured follow-up plan and EMR implemented guidelines echoes The Institute of Medicine’s landmark report *From Cancer Patient to Cancer Survivor: Lost in Transition* findings of the fundamental need for survivorship care plans and improved care coordination to improve the quality of cancer care²⁴²⁵. They preferred the oncologists manage cancer-related medical issues, screen for cancer recurrence and secondary cancers. As noted above, this is not surprising given the rarity of this patient population and suggests an area which is amenable to collaborate care between PCPs and hematologist-oncologists.

Not unexpectedly, greater clinical experience, both in general and specifically with hematologic malignancy and HCT survivors, was associated with higher reported confidence in managing general health as well as cancer related issues in this patient population. This finding is in accordance with a study done in internal medicine and family medicine residents which reported greater clinical experience being associated with higher knowledge and confidence in managing cancer related issues in cancer survivors²⁶. Although there is no substitute for experiential learning, we do identify PCP groups who may benefit from directed educational interventions on this topic. Future studies can focus on identifying best practices that may be shared with other PCPs to help facilitate survivorship care.

Some limitations of our study need to be acknowledged. The response rate for our survey was relatively low, but not atypical for physician directed surveys. Our PCPs work in an integrated healthcare system that cares for a relatively larger number of hematologic malignancy patients and HCT recipients, and it is possible that barriers faced by PCPs who work in a community practice setting may be different and more pronounced compared to what we observed. We also acknowledge the limitations of a survey that cannot provide a detailed perspective of practice patterns and barriers. There was a difference in response rates between the two sites, which is likely related to the number of PCPs who practice at the two institutions and the resultant engagement to participate in the survey.

The growing hematologic malignancy and HCT survivor population and the complexities involved in their long-term care heighten the need for more efficient and effective approaches to survivorship care delivery. The current study has highlighted concerns and challenges faced by PCPs in caring for this patient population. Priority should be given to the training of PCPs in survivorship care and earlier involvement during the course of cancer treatment. There is a lack of evidence regarding best practices for survivorship care and developing an evidence-based model of care would be beneficial²⁷. The optimal model for providing care to long-term survivors with hematologic malignancies and HCT will require multidisciplinary care with a close partnership between specialty cancer and transplant centers, patient's PCPs and other healthcare providers^{2, 5, 28}.

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CLINICAL PRACTICE POINTS

Long-term survivors of hematologic malignancies and hematopoietic cell transplantation (HCT) frequently receive healthcare through their primary care physicians (PCPs) and are less likely to be under the care of cancer centers and hematologist-oncologists. Barriers faced by PCPs in caring for this patient population have not been well described. Using a web-based survey of PCPs employed in two large integrated healthcare systems, we identify perceived barriers to delivery of care to hematologic malignancy/HCT survivors, resources available to care for cancer survivors, practices for care coordination with hematologist-oncologists, and preferred models of care delivery. Common barriers identified by PCPs included lack of resources to facilitate care (69%), lack of awareness of screening/prevention guidelines (55%) and psychosocial needs of survivors (65%), inadequate time (65%), and patient preference to follow up with their oncologists (66%). They expressed confidence in caring for general medical issues (84%) and general cancer screening (73%), but preferred oncologists manage cancer related medical issues (42%), screen for cancer recurrence (52%) and secondary cancers (55%). PCPs who had previously cared for larger number of hematologic malignancy/HCT survivors and those further out since graduation from medical school reported greater confidence in managing cancer related medical issues. Our study highlights several barriers faced by PCPs in providing care to hematologic malignancy/HCT survivors. However, several of these barriers are potentially addressable by education of PCPs focused on issues relevant to this patient population, development of evidence-based guidelines, implementation of clinical decision support tools, enhancing clinical experience, and better care coordination with hematologist-oncologists.

Fig. 1a.
Challenges in caring for cancer survivors in general

Fig. 1b.
Challenges in caring for cancer survivors in general

Fig. 1c.
Service provider preferences for providing care for hematologic malignancies and HCT survivors

Fig. 2a.

Case scenario of patient with acute myeloid leukemia treated with chemotherapy only

Fig. 2b.

Case scenario of patient with acute myeloid leukemia treated with an allogeneic HLA-identical sibling donor transplant.

Table 1:

Characteristics of survey respondents

Characteristic	N	%
Respondents	86	
Institution		
Cleveland Clinic, Ohio	59	69
Mayo Clinic, Arizona	27	31
Primary site of practice		
Main campus	34	40
Satellite clinic/hospital	62	60
Primary specialty		
Internal Medicine	60	70
Family Medicine	21	24
Medicine-Pediatrics	5	6
Years since graduation from medical school *		
Median (range)	17	1–47
Currently teaching medical students or residents		
Yes	68	79
No	18	21
Number of patients seen in a typical week		
<25	9	11
26–50	18	21
51–75	32	37
76–100	19	21
>100	9	11
Number of hematologic malignancy/HCT survivors cared for in last 5 years		
0	6	7
1–5	31	36
6–10	21	24
11–20	9	11
>20	19	22

HCT indicates hematopoietic cell transplantation

* N=85 respondents

Table 2:

Associations between PCP characteristics and survey responses

Domain	Primary specialty	Practice location	Teach students/residents	PCP characteristic*	See larger number of patients per week	Care for larger no. of heme malignancy/HCT survivors
Practices for care delivery and care coordination with hematologist-oncologists for cancer survivors in general[†]						
- Receive comprehensive treatment summary and care plan	-	-	-	↑	-	↑
- Receive updates and summary in a timely manner	-	-	-	↑	-	↑
- Difficulty transferring patient care responsibility	-	-	-	-	↑	-
- Discuss screening for cancer recurrence, late effects and 2 nd cancers	-	-	-	-	-	↑
Knowledge and care delivery related barriers for cancer survivors in general[‡]						
- Lack resources to facilitate survivor care	-	-	-	-	-	↓
- Lack awareness of clinical and psychosocial needs	-	-	-	↓	-	-
- Lack awareness of screening and prevention guidelines	-	-	-	↓	↓	-
- Insufficient time for providing survivorship care	-	-	-	-	↑	-
- Insufficient reimbursement for providing survivorship care	-	-	-	-	↑	-
- Inadequate communication with hematologist-oncologist	-	-	-	-	-	↓
- Patients prefer followup with hematologist-oncologist only	-	-	-	-	-	-
- Patient unclear who to approach for health issues	-	-	-	-	-	-
Preference for care delivery for hematologic malignancy and HCT survivors[‡]						
- Management of general medical issues	-	-	↑	-	-	-
- Management of medical issues related to cancer therapy or HCT	-	-	-	-	-	-
- Screening for cancer recurrence	-	-	-	-	-	↑
- General cancer screening	-	-	↑	-	-	↑
- Secondary cancer screening	-	-	-	-	-	↑
- Management of psychosocial issues	-	-	↑	-	-	-
- Management of fertility issues	-	-	-	-	↑	↑
AML chemotherapy only survivor case scenario[#]						

Domain	Primary specialty	Practice location	Teach students/residents	PCP characteristic*	See larger number of patients per week	Care for larger no. of heme malignancy/HCT survivors
- Management of general medical issues	-	-	↑	-	-	-
- Management of medical issues related to cancer therapy or HCT	-	-	-	↑	-	↑
- Screening for cancer recurrence	-	-	-	↑	-	↑
- Secondary cancer screening	-	-	-	-	↑	↑
AML HCT survivor case scenario#						
- Management of general medical issues	-	-	-	-	-	↑
- Management of medical issues related to cancer therapy or HCT	-	-	-	↑	-	↑
- Screening for cancer recurrence	-	-	-	↑	-	↑
- Secondary cancer screening	-	-	-	-	-	↑

AML – acute myeloid leukemia; HCT – hematopoietic cell transplantation; PCP – Primary care physician

* Shaded areas show significant associations (light gray $P < 0.05$, dark gray $P < 0.01$) with arrows indicating the direction of association

† Analysis compared “never” and “rarely” (combined) vs. “often” and “always” (combined); table shows any association towards “often/always” response

‡ Analysis compared “never” and “rarely” (combined) vs. “often” and “always” (combined); table shows any association towards “often/always” response

§ Analysis compared “never” and “rarely” (combined) vs. “often” and “always” (combined); table shows any association towards “often/always” response

Analysis compared “never” and “rarely” (combined) vs. “often” and “always” (combined); table shows any association towards “often/always” response

Table 3:
Multivariable analysis of PCP characteristics and confidence in managing survivorship issues in AML case scenarios

Domain and PCP characteristics	AML chemo only survivor case scenario		AML HCT survivor case scenario	
	Odds ratio (95% CI)	P-value	Odds ratio (95% CI)	P-value
Confidence in managing general medical issues that may or may not be related to cancer				
Currently teach medical students/residents	3.97 (1.30–12.1)	0.015	-	
Care for larger number of hematologic malignancy/HCT survivors [‡]	-		1.71 (1.06–2.77)	0.028
Confidence in managing cancer related medical issues				
Increasing time since graduation [*]	2.10 (1.15–3.81)	0.015	2.35 (1.27–4.36)	0.006
Care for larger number of hematologic malignancy/HCT survivors [‡]	1.92 (1.32–2.80)	<0.001	1.72 (1.18–2.49)	0.004
Confidence in screening for cancer recurrence				
Increasing time since graduation [*]	2.53 (1.38–4.64)	0.003	1.94 (1.09–3.45)	0.024
Care for larger number of hematologic malignancy/HCT survivors [‡]	1.47 (1.04–2.08)	0.028	-	
Confidence in screening for secondary cancers that may be related to cancer therapy				
Care for larger number of hematologic malignancy/HCT survivors [‡]	1.51 (1.08–2.11)	0.016	1.50 (1.07–2.11)	0.018

AML – acute myeloid leukemia; HCT – hematopoietic cell transplantation; PCP – Primary care physician

^{*} Categorized as <10, 11–20, >20 years since graduation

[‡] Categorized as 0, 1–5, 6–10, 11–20, >20 hematologic malignancy/HCT survivors cared for