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Support for Young Adult Cancer Patients: Perspectives of Patients and their Mothers

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Abstract
The shift from adolescence to adulthood is marked by increased independence from parents. The purpose of this research is to describe types of beneficial support and concordance between young adult cancer patients/survivors and their parents. One-on-one phone interviews were conducted. Data were analyzed with constant comparison and linguistic methods. Fifteen patients and eight mothers participated. Support types most cited included informational, tangible, and emotional. The greatest difference between patients and mothers was in mention of emotional or tangible support. Continued attention to the role of parental support for young adult cancer patients is important for care.

Keywords Adulthood · AYA · Support · Psychosocial

Young adults, those 19–29, often see themselves as "in between," moving towards independence, but still closely tied to their parents [3]. Young adult cancer patients navigate this transition while also often needing support from parents as caregivers. Young adult cancer patients may require months or years of follow-up care, requiring an extended reliance on parent caregivers for psychosocial support.

Conflict may arise due to the differing views of what kind of support patients and parents believe to be the most beneficial [21]. Tension may exist for parents who want to maintain control, but at the same time want to allow their adult child to make their own decisions [2, 12, 15]. As such, establishing roles for support that work for patients and parents is important to prevent conflict from developing, reduce distress for patients and caregivers, and ensure patients receive the best care possible.

The aim of this research is to describe what types of social support (tangible, emotional, informational) young adult cancer patients and their parents perceived to be most beneficial during the cancer care trajectory, and if those described supports were in alignment.

Methods

This study received approval from the University of South Florida Institutional Review Board. Informed consent was obtained from all individual participants included in the study.

Recruitment

Participants were recruited from the Adolescent and Young Adult clinic at an NCI-designated Comprehensive Cancer Center. Criteria for patient inclusion included (1) age 19–29 at the time of the interview; (2) diagnosis of cancer between ages of 19–29 and receiving current treatment or follow-up care at the cancer

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center; and (3) there was a parent providing support for the patient. The research team contacted each potential participant by phone, and patients who agreed to participate were asked to refer a mother/father. Patients could participate without referring a parent, but parents were ineligible to participate on their own.

Of 28 eligible patients, 10 could not be reached by telephone. Three patients declined to participate. Of the 15 patients who agreed to participate, 11 referred a mother. Three parents declined to participate.

Interviews

Research staff trained in qualitative methods conducted all interviews over the phone to allow for maximum convenience for participants. Using a semi-structured interview guide, all participants were asked to describe the ideal and actual role of parents in supporting young adult patients (two questions), and to provide examples of this support. All interviews were audio recorded and professionally transcribed verbatim. Demographic information was also obtained.

Data Analysis

We used two stages of iterative thematic analysis when reviewing the transcripts: constant comparison and keyword analysis. First, transcripts were segmented by page and coded using NVivo software [16] by two trained coders. Types of support were categorized by role (patient or mother) and by categorizing support type using a code book developed based on social support definitions (2003) [8, 11] and refined through traditional constant comparison methods [5].

Next, we used AntConc software for keyword analysis based on words identified within passages of text coded in the first stage [1]. When combined with thematic coding using constant comparison, keyword analysis is a useful validation tool and can increase reliability and validity [6]. The words/word stems for each type of support are listed in Table 1. Coders reviewed passages identified through this method to determine context and capture potentially missed passages in stage 1. Kappa ≥ 80% was achieved for all codes. Table 1 lists the definitions of the three types of support.

Table 1 Support type definitions and search terms

Support type	Definition	Search terms
Informational	Provision of information about the cancer experience, such as treatment and things to expect.	inform*, understand*, experience*
Tangible	Tasks done for the patient, such as transportation to appointments, watching children, or assisting with finances.	appointment*, finance*, cook*, clean*, transport*, drive*, kid*/child*
Emotional	Provision of empathy and compassion to the patient, often through “being there” and providing a listening ear.	cry*, be* there, listen*, emotion*, comfort*

An asterisk at the end of the word allows the AntConc software to identify inflections of the base word

Results

Demographics

The study sample includes 15 patients and eight mothers (Table 2). Most participants were White (66%). The majority of patients were male (60%), and all of the parents were mothers of the patients. Interviews lasted an average of 35.5 min (range 14 to 57).

Support Themes

Informational A higher proportion of mothers (4/8) than patients (6/15) discussed informational support (Fig. 1). Only two of eight parent-child dyads both mentioned informational support. Information about treatment was sought by patients and parents directly from medical professionals, and from family, friends, and online resources. Often, patients relied on a parent to help them understand the information.

> There was a lot of things that I didn’t understand and my mom was the one that I went to. I would ask her, ‘Hey, is this the way I should go?’ ‘Is this what I should do?’ ‘Explain it to me’. (male patient, 22, Study ID 105)

In addition to providing support to the young adult child, some mothers discussed needing informational support for themselves:

> Honestly, it would be helpful if there was someone who had gone through the same thing to guide us through all the steps because the biggest fear you have is the unknown…It’s unbelievable and the first thing you do is go online which is the biggest mistake you could ever do because…it’s all bad prognosis and it just puts you in a depression spiral like no tomorrow. (mother of a 21-year-old patient, Study ID 304)

Tangible All mothers (8/8) and 67% of patients (10/15) mentioned tangible forms of support, with overlap in three of eight parent-child dyads. Patients perceived tangible forms of support as important to free up their time to focus

Table 2 Participant demographics

	Patients (*N* = 15)		Parent caregivers (*N* = 8)	
Variable	*n*	%	*n*	%
Age	Range 21–29 Median 26	–	Range 46–60 Median 56.5	–
Sex, n (%)				
Female	6	40.0	8	100.0
Race				
Black or African American	2	13.3	2	28.6
Asian	1	6.7	1	14.3
White or Caucasian	10	66.7	4	57.1
Other	2	13.3	0	0.0
Latino/a	4	26.7	2	28.6
Education				
Less than high school	2	16.7	0	0.0
High school graduate or equivalent	6	40.0	2	28.6
Some college or vocational school	5	33.3	2	28.6
College graduate or higher	2	13.3	3	42.9
Employment				
Unemployed	4	26.7	1	14.3
Student	1	6.7	1	14.3
Part-time	1	6.7	0	
Full-time	9	60.0	3	42.9
Religious affiliation				
Baptist	2	13.3	1	14.3
Catholic	3	20.0	1	14.3
Presbyterian	0	0.0	2	28.6
Other Christian	4	26.7	3	42.9
Pagan	1	6.7	0	0.0
No religious affiliation	4	26.7	0	0.0
No answer	1	6.7	0	0.0
Financial status				
Not very good	2	13.3	2	28.6
Comfortable	10	66.7	5	71.4
More than adequate to meet needs	3	20.0	0	0.0
Annual household income				
Less than 10,000	2	13.3	0	0.0
10,000–24,999	2	13.3	2	28.6
25,000–39,999	3	20.0	1	14.3
40,000–49,999	1	6.7	0	0.0
50,000–74,999	1	6.7	2	28.6
75,000 or more	3	20.0	1	14.3
Prefer not to answer	1	6.7	1	14.3
Do not know	2	13.3	0	0.0
Marital status				
Single	8	53.3	0	0.0
Married	5	33.3	5	71.4
Divorced	1	6.7	1	14.3
Other	1	6.7	1	14.3

Table 2 (continued)

	Patients (*N* = 15)		Parent caregivers (*N* = 8)	
Share residence with patient	n/a	n/a	3	37.5
Diagnosis				
Osteosarcoma	4	26.7	n/a	n/a
Breast cancer	3	20.0	n/a	n/a
Brain/nervous system tumor	2	13.3	n/a	n/a
Other soft tissue sarcoma	3	20.0	n/a	n/a
Other	3	20.0	n/a	n/a

n/a, not available

on healing. Participants mentioned several specific tasks, including watching children, transportation assistance, cooking, and cleaning.

> I thought it was more important to cook for me, and bring me things and just make sure I was okay in terms of that. I think emotionally and physically people just need to relax and rest and take care of themselves and let their bodies heal. You don't need somebody constantly in your face. I didn't, at least. (female patient, 27, Study ID 111)
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> Most helpful would be taking care of the rest of the family. Taking care of the children. (male patient, 29, Study ID 113)

Both patients and mothers brought up moving back in with parents as an important form of tangible support. Patients and mothers saw parents as a safety net in this regard, although some patients acknowledged it was a shift from being newly independent to having to rely on mom and dad again.

> …taking on anything they can off the child's shoulders so they don't have to worry about it… like letting them stay with them rather than having to be out there on their own by themselves. That way they're around family. (mother of a 22-year-old patient, Study ID 305)
>
> From a parent, just someone that you know…if anything goes the absolute worse, that you at least have your parents to go back to just like any other situation in life. You move out of the house. You go get an apartment with your buddy and that falls through. Where do you go? Back to your parents. That's always the best role for a parent in terms of support is to just be there in case. (male patient, 21, single, Study ID 104)

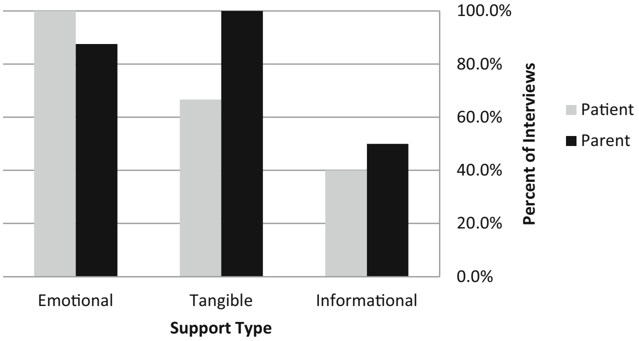

Fig. 1 Percent of interviews where support types were discussed

Emotional The desire for emotional support was expressed by 100% of patients (15/15) and 87.5% of mothers (7/8), with overlap in seven of eight dyads. Often emotional support was described as just "being there" and providing a listening ear despite reports from both patients and parents that parents were unable to completely relate to or understand the patient experience.

> I would say…to comfort, to listen, to listen to them, to comfort them. Just to be there because I'm not a doctor. I wouldn't know what else to do. (mother of a 27-year-old patient, Study ID 303)
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> In a perfect world, I think they [parents] should always be there…even though they actually don't know [what it is like] or they can't be in our shoes [or] they don't really have the knowledge of what we're going through. (female patient, 27, Study ID 103)

Although there was a strong desire by patients for parents to be present during the cancer experience, some patients also suggested that parental support could also be overwhelming:

> There have been times that I've had to and just kind of walk away and go take my own time. (male patient, 21, Study ID 104)

> Every time I have chemo, my mom's there. She calls me after… She's very supportive. I mean, it can be very disturbing sometimes, but I know it's just out of love. (Male patient, age 27, Study ID 110)

Discussion

Our findings describe types of support that both parents and patients found helpful, and corroborate with previous research that indicates the provision of support for individuals coping with cancer is a dynamic process including multiple forms of support from caregivers [18]. While all forms of support can be useful, the majority of mothers and all patients mentioned emotional support in our study, suggesting this was particularly important. This type of support in particular has been linked to quality of life in cancer patients [4].

Both patients and mothers in our sample described informational support least often. Patients and parents may be learning as they go and independently seeking informational support from other sources, such as the oncologist or the internet [19]. Although we found that patients often rely on their parents for information and advice, it was recognized that there were others with more expertise. In this case, other forms of support could be perceived as the most beneficial and desirable from parents [7, 10, 11, 20]. For example, though not explicitly described in depth in our interviews, many cancer patients struggle to pay for their care and financial support can be an important tangible resource that parents may be able to provide to reduce the financial toxicity of cancer [9].

Conflict may arise due to the differing views of what kind of support patients and parents believe to be the most beneficial [21]. Tension may exist for parents who want to maintain control, but at the same time want to allow their adult child to make their own decisions [2, 12, 15]. Differences in the types of support provided/desired can have important implications for patient psychosocial adjustment. Research in adult cancer populations suggests that both receipt of unwanted support and a lack of desired support predict poorer psychological adjustment [13, 14, 17]. The impact of this mismatch may vary across the lifespan. For example, some young adult patients may be able to meet their own tangible needs more completely than parents believe, resulting in a higher value of parental emotional support for patients. The shift from adolescence to young adulthood includes increased responsibility [2], so parents may perceive the alleviation of responsibility as a more beneficial reduction in their child's newly-acquired stressors. However, maintaining newly-acquired responsibilities and autonomy might be more important to the patient's development.

Limitations

The participants in this study had relatively high resources and low conflict; some selection bias may have occurred. In a broader population where limited resources are more of a concern, there may be more distinct differences in support needs and expected roles. Future research should include a larger sample size, and the opinions of partners, especially spouses, and fathers.

Conclusion

Although patients and mothers agreed that any support is helpful, they have distinct expectations about the type of support parents should provide. Understanding those expectations can help health care providers navigate the young adult cancer caregiving experience and mediate potential conflicts that arise when provided support does not match expectations.

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Compliance with Ethical Standards

Author Disclosure Statement The authors declare that they have no conflict of interest.

Ethical approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. This article does not contain any studies with animals performed by any of the authors.

Statement of Informed Consent Informed consent was obtained from all individual participants included in the study.

References

1. Anthony L (2018) AntConc (Version 3.5.7) [Computer Software]. Waseda University, Tokyo. Available from http://www.laurenceanthony.net/software
2. Aquilino WS (2006) Family relationships and support systems in emerging adulthood. In: Arnett JJ, Tanner JL (eds) Emerging adults in America: coming of age in the 21st century. American Psychological Association, Washington, DC, pp 193–217. https://doi.org/10.1037/11381-008
3. Arnett JJ, Žukauskienė R, Sugimura K (2014) The new life stage of emerging adulthood at ages 18–29 years: implications for mental health. Lancet Psychiatry 1(7):569–576
4. Arora NK, Finney Rutten LJ, Gustafson DH, Moser R, Hawkins RP (2007) Perceived helpfulness and impact of social support provided by family, friends, and health care providers to women newly diagnosed with breast cancer. Psychooncology 16(5):474–486
5. Corbin J, Strauss A (2008) Basics of qualitative research: techniques and procedures for developing grounded theory, 3rd edn. SAGE Publications, Thousand Oaks

6. Cortes V (2015) Using corpus-based analytical tools to study patient talk. In: Anton M, Goering E (eds) Understanding patients' voices: a multi-method approach to health discourse, Ch. 4. John Benjamins Publishing Co., Amsterdam, pp 51–70
7. Covelli AM, Baxter NN, Fitch MI, McCready DR, Wright FC (2015) 'Taking control of cancer': understanding women's choice for mastectomy. Ann Surg Oncol 22(2):383–391
8. Cutrona CE, Russell DW (1990) Type of social support and specific stress: toward a theory of optimal matching. In: Sarason IG, Sarason BR, Pierce GR (eds) Wiley series on personality processes. Social support: an interactional view. Wiley, Oxford, pp 319–366
9. Goldstein DA (2017) Financial toxicity in cancer care-edging toward solutions. Cancer 123(8):1301–1302. https://doi.org/10.1002/cncr.30555
10. Helgeson VS (1992) Moderators of the relation between perceived control and adjustment to chronic illness. J Pers Soc Psychol 63(4):656–666
11. Helgeson VS (2003) Social support and quality of life. Qual Life Res 12(Suppl. 1):25–31
12. Lindell AK, Campione-Barr N (2017) Continuity and change in the family system across the transition from adolescence to emerging adulthood. Marriage Fam Rev 53(4):388–416
13. Linden W, Vodermaier A (2012) Mismatch of desired versus perceived social support and associated levels of anxiety and depression in newly diagnosed cancer patients. Support Care Cancer 20(7):1449–1456
14. Merluzzi TV, Philip EJ, Yang M, Heitzmann CA (2016) Matching of received social support with need for support in adjusting to cancer and cancer survivorship. Psychooncology 25(6):684–690
15. Parra A, Oliva A, del Carmen Reina M (2015) Family relationships from adolescence to emerging adulthood: a longitudinal study. J Fam Issues 36(14):2002–2020
16. QSR International Pty Ltd. (2012) NVivo qualitative data analysis software
17. Reynolds JS, Perrin NA (2004) Mismatches in social support and psychosocial adjustment to breast cancer. Health Psychol 23(4):425–430
18. Sippel LM, Pietrzak RH, Charney DS, Mayes LC, Southwick SM (2015) How does social support enhance resilience in the trauma-exposed individual? Ecol Soc 20(4):10
19. Stinson JN, White M, Breakey V, Chong AL, Mak I, Low KK, Low AK (2011) Perspectives on quality and content of information on the internet for adolescents with cancer. Pediatr Blood Cancer 57(1):97–104
20. Warren M (2010) Uncertainty, lack of control and emotional functioning in women with metastatic breast cancer: a review and secondary analysis of the literature using the critical appraisal technique. Eur J Cancer Care 19(5):564–574
21. Zebrack B, Isaacson S (2012) Psychosocial care of adolescent and young adult patients with cancer and survivors. J Clin Oncol 30(11):1221–1226