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Maybe what seems so right is wrong

A medical condition media-generated money can't cure

With bone marrow transplants, beating the media drums for donors is of more symbolic than literal help.

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It seems like such a good idea: good for journalism, good for the community. When a local family launches a desperate search for the bone marrow donor and funds that will save their child's life, it's only natural that they ask local media for help.

When a child will certainly die unless the family can find a donor and raise \$200,000 to pay for the life-saving treatment, what local station or newspaper could resist broadcasting the plea?

It's the kind of story in which news media both observe and incite an outpouring of community support. It's the kind of story that editors and publishers carry in their hip pockets to refute accusations that "you only publish the bad news."

And, in this form, the story just ought not be done.



editors and news directors single out which sick people merit media assistance, they are literally choosing who lives and who dies.

These individual stories of desperation should also not be told if telling them consumes air time and column inches that could be spent giving readers accurate information on bone marrow transplantation. Both can be done, but most often fundraising frenzy and human drama replace the stories that can help citizens improve a hurting system.

Bone marrow transplants are part of a new and rapidly developing technology. It is the only hope for patients with a variety of cancers and blood disorders. But that hope may be no more than a 20-30% chance of survival.

The bone marrow stories promoted by professional fundraisers who represent individual patients and by bone marrow registries often perpetuate false hope and myths about the treatment. The myths are damaging both to desperate patients and to the public.

Myth: Community drives to type potential bone marrow donors will result in finding bone marrow for the local patient in need.

Some donor registry representatives say that there's never been a time when a local call for bone marrow donors resulted in finding the needed match. The most optimistic say it sometimes happens that a local volunteer will match the local patient, but very rarely.

Since there is little, if any, chance that the volunteer will match and actually have to donate, the altruism is symbolic rather than literal. But, "minute-ten" packages do not explain symbolic gestures well. The public and the donors are misled about who really benefits. If participating in such a drive delays a patient's exhaustive search of all available registries, the fiction can be fatal.

The patient may rarely benefit, but the sponsoring bone marrow registry that lends organizational expertise always does. It adds new typed volunteers to its list of potential donors. And it builds its list on the patients' need. The \$75 per volunteer typing fee is paid by the patient's family or by volunteers when, realistically, there is almost no hope that the patient will get a chance for life in this way.

Myth: Typed volunteers are potential marrow donors for other patients in other parts of the country.

Maybe. Patients have to know to check out multiple registries, have to have enough funds for multiple searches. And the typed volunteer must be interested in more than becoming a local hero.

The National Bone Marrow Registry is one possible source of bone marrow donation. It boasts 370,000 typed volunteers. If no match is found there, patients who know of other groups will try the Caitlin Raymond International Registry, which claims an additional 40,000 typed volunteers in the states and access to 250,000 overseas.



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The matched patient has to hope that the typed volunteer won't back out. Someone motivated by media-hyped donor drives to become a local hero by donating marrow to the little girl down the street won't be interested in enduring the painful harvesting process months or years after the local patient has died.

Myth: Patients in need of funding for their bone marrow transplant will die if not for private philanthropy.

There are other possibilities, possibilities easily forgotten as reporters exclaim over the youngster who gave his piggy bank to help a classmate.

Insurance companies could pay for bone marrow transplantation, as could state medicaid programs. Or, if the treatment is truly experimental, as some of these payers claim, federal research funds could be set aside for the treatment. Or the federal government could pick up the cost, using the same argument it now offers for national access to kidney transplants: It's cheaper to do the transplants than to maintain patients with the less curative types of treatment.

Each individual case of need provides opportunities for exposing these real issues of bone marrow transplant. But usually audiences don't get the economists explaining how expensive heroic health care fits into personal and public finances. Nor are they provided policymakers forced to explain why solid organs and blood are managed nationally but bone marrow is not. Instead, the stories offer fundraisers and family who thank the community on behalf of little Jimmy.

News media perpetuate an unfair system when they help raise funds for individuals and fail to question the assumption that needy people must pay or die. News media share in society's moral burden of allowing the wealthy to hoard the right to life.

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