Running head: Beliefs about joining a bone marrow registry

Identifying belief targets to increase bone marrow registry participation among students who
have never donated blood

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Abstract

New members on bone marrow registries worldwide are needed to allow sufficient diversity in the donor pool to meet patient needs. We used the theory of planned behaviour belief-basis and surveyed students who had not donated blood previously (i.e. non-donors) (N = 150) about the behavioural, normative, and control beliefs informing their intentions to join the Australian Bone Marrow Donor Registry. Key beliefs predicting non-donors' intentions included: viewing bone marrow donation as an invasion of the body ($\beta = -.35$), normative support from parents ($\beta = .40$), anticipating pain/side effects from giving blood ($\beta = -.27$), and lack of knowledge about how to register ($\beta = -.30$). Few non-donors endorsed these beliefs, suggesting they are ideal targets for change in strategies encouraging bone marrow donor registration.

Introduction

Each year thousands of people, in Australia alone, are diagnosed with fatal blood disorders such as Leukaemia and Hodgkin's lymphoma (The Leukaemia Foundation, 2008a). One viable treatment that may save or improve quality of life is a bone marrow (BM) transplant (including Hematopoietic Stem Cells) from a compatible donor. While 30% of people find a donor match within their family, the vast majority rely on national BM donor registries, such as the Australian BM Donor Registry (ABMDR), to find a suitable match (Australian Bone Marrow Donor Registry [ABMDR], 2010a). As of December 2009, 173,257 donors were registered on the ABMDR (ABMDR, 2010b). Potential donors aged 18-40 years are recruited for the register and donors are retired from the ABMDR at 60 years of age. It is critical to maintain the balance of donors on the registry and to recruit a larger pool of donors to ensure sufficient diversity is available to meet the needs of patients (ABMDR, 2010). Currently there is an insufficient pool of BM donors to meet demand (Glasgow & Bello, 2007). Understanding people's motivations to register as a BM donor is important to increase the pool of potential donors and offer life-saving or improving treatment.

Joining the BM donor registry likely involves contemplating risks associated with donation including anticipating pain and side-effects related to the BM/stem cell donation (Glasgow & Bello, 2007), as well as the potential to be called upon to donate once registered. Also, joining the ABMDR requires a blood sample for tissue typing. For new or novice donors, giving a blood sample involves overcoming a fear of needles and blood (Armitage & Conner, 2001; Giles, McClenahan, Cairns, & Mallet, 2004), anticipated side-effects (fainting or other vasovagal reactions, France, Ditto, France, & Himawan, 2008; Sauer & France, 1999) and potentially discovering an illness or disorder (Sojka & Sojka, 2008). Therefore, people's motivations to join a BM registry may be informed by beliefs related to three aspects: blood donation, BM donation, and registration.

Despite the need to increase the donor pool (Glasgow & Bello, 2007) and the discrepancy between donation willingness and actually joining a BM registry (Onitilo et al., 2004), the majority of research has focused on the process of donating BM (Bagozzi, Lee, & Van Loo, 2001; Glasgow & Bello, 2007; Switzer et al., 2003) rather than decisions to join a BM registry. One exception is Norvilitis and Riley (2001) who compared donors and non-donors on variables including personality, self-competency, life satisfaction, and fear of medical procedures. They found that busy schedules, fear, and lack of education were common reasons preventing non-donors from registering, and fear of needles and pain were deterrents. Normative support (or lack thereof) from friends and family may also inform BM donation and registration decision-making (Norvilitis & Riley 2001; Studts, Ruberg, McGuffin, & Roetzer, 2010; Stukas, Dew, Switzer, & Simmons, 1999).

Acknowledging the importance of beliefs, Glasgow and Bello (2007) used the Theory of Planned Behaviour (TPB; Ajzen, 1991) belief-basis as a framework to explore African Americans' BM donation intentions. The three most commonly identified beliefs in the qualitative phase of this study were "painful experience for the donor" (41%), "health concerns for the donor" (38%), and "family's approval" (26%) (p. 373). Consistent with Glasgow and Bello and donation studies in other contexts (Armitage & Conner, 2001; Hyde & White, 2007) we adopted the TPB belief-basis for our study.

Using the TPB to identify key belief targets for future interventions

The TPB belief framework refers to advantages and disadvantages (behavioural beliefs), perceived referents approving or disapproving (normative beliefs), and barriers preventing or motivators facilitating (control beliefs) behaviour. These beliefs relate to a person's intentions and subsequent behaviour (Ajzen, 1991). Traditionally, beliefs were assessed using a multiplicative combination of a belief and evaluative item (behavioural beliefs x outcome evaluations; normative beliefs x motivation to comply, and control beliefs

x perceived power). However, these evaluative items are not essential for belief measurement (Ajzen, 1991) and have not been included in our study (Hamilton & White, 2011; Hyde & White, 2009a).

Several researchers (e.g., Fishbein & Yzer, 2003; Francis et al., 2004) note these behavioural, normative, and control beliefs can inform interventions to encourage/discourage behaviour. Hornik and Woolf (1999) outline three criteria to select target beliefs for behaviour-change (see Fishbein, von Haeften, & Appleyard, 2001; Fishbein & Yzer, 2003; Hamilton & White, 2011). First, for the population investigated, there should be a strong relationship (significant correlation or predictive relationship) between the belief and outcome measure (intention or behaviour). Second, the number of people who hold the belief should not be substantial so that a large proportion of the population could be encouraged to change their belief. Third, the researcher must evaluate whether a realistic argument and evidence can be provided to encourage the target population to change their belief.

The Current Study

Deciding to join a BM registry likely involves many of the beliefs that inform decisions for a first-time blood donor; however, our study offers insight beyond the blood donor experience. BM donation is perceived by the general population as a more invasive and painful procedure. Donating blood is a volitional choice made at a time and place convenient to the donor whereas joining a BM registry means that a person could be called upon to donate at a future point that is not of their choosing (and possibly more than once). Accordingly, the decision to join a BM registry may include beliefs related to blood donation as well as to other aspects of BM donation and registering. Furthermore, joining a BM registry involves giving a blood sample and the beliefs of first-time blood donors are likely to differ from experienced donors (Masser, White, Hyde & Terry, 2008). To avoid any potential confound of prior donation experience on beliefs we focussed on people who have never

donated blood (i.e. *non-donors*). Our aims were two-fold. First, we explored people's behavioural, normative, and control beliefs and intentions for joining a BM registry. Second, we used Hornik and Woolf's (1999) criteria to identify target beliefs that could encourage non-donors to join the ABMDR.

Method

Participants

Participants were predominantly female (67%) university students ($N = 150$) who had not previously donated blood. Participants were aged 18-40 years ($M_{age} = 21.4$; $SD = 4.6$) and in good health making them ideal candidates for donation.

Design and Procedure

As part of a larger experimental study on risk and BM registration decisions (McLaren, Hyde, & White, 2012), students from a large university in Queensland, Australia were approached in lectures or on campus and invited to complete either an online (via a link provided on a recruitment flyer) or paper version of a questionnaire. Students were informed that participation was voluntary, anonymous and confidential and received either research participation credit or a chocolate for their participation.

Measures

Target behaviour. The target behaviour was joining the ABMDR in the next 6 months. Participants received a definition outlining the steps required to join the ABMDR: (1) making an appointment with the Australian Red Cross Blood Service to donate blood, (2) completing a consent form to join the registry, and (3) donating blood for testing and tissue typing. We did not measure actual registration behaviour; instead, we used intentions as a proxy measure of behaviour (Ajzen, 1991).

Intention. Four items measured intention to join the ABMDR on 7-point Likert scales scored 1 (*strongly disagree*) to 7 (*strongly agree*) and formed a reliable scale ($\alpha = .93$). The

four items were: “I intend to”, “I would be willing to”, “I plan to”, and “I will make an effort to” join the ABMDR in the next 6 months”.

Beliefs. Consistent with TPB specifications (Ajzen, 1991), an elicitation study was conducted initially with 20 university students (16 female) who were in good health and aged 18-40 years ($M_{age} = 26.0$, $SD = 5.4$) to identify salient behavioural, normative, and control beliefs about joining the ABMDR. We used content analysis to identify behavioural, normative, and control beliefs commonly reported by 25% of the sample or more for use in the main study questionnaire (Table 1).

Participants rated the likelihood that nine behavioural beliefs (three advantages and six disadvantages), eight normative beliefs, and 16 control beliefs (10 barriers and six motivators) would occur if they joined the ABMDR in the next 6 months. Beliefs were measured using 7-point Likert-type scales scored 1 (*extremely unlikely*) to 7 (*extremely likely*). Belief scales were not created and internal consistency measures are not reported because belief scales are not expected to be internally consistent. A degree of ambivalence about beliefs is likely to exist because people may value some beliefs positively and others negatively and these beliefs are not expected to correlate highly with each other (Ajzen, 2006). In our study, individual beliefs are of interest to identify targets for change.

Demographics. Sex (*male, female*), age in years, and self-reported BM donation knowledge (“Overall, how would you rate your knowledge of the topic of BM donation?” 1 *very poor* to 7 *excellent*) were included.

Data Analysis Strategy

Descriptive analyses determined the distribution of the sample by age, sex, and self-reported BM donation knowledge. Correlations between belief items and intentions were examined (Table 1). In line with Hornik and Woolf’s (1999) first criteria, we conducted a series of multiple regressions with each belief set (behavioural, normative, control barrier,

and control motivator beliefs) regressed onto intention to test the strength of the relationship between the belief and outcome measure (Table 2). Initially, we controlled for any effects of the unsuccessful experimental manipulation from the larger study by entering the condition (risk information vs. none) variable in the first step of analyses. Condition was not a significant predictor of intention and is not included in the analyses presented here. In line with Hornik and Woolf's second criteria, the percentage of non-donors who fully or strongly endorsed a belief that was a significant predictor of intention was examined for the possibility of belief-change (Table 2). For Hornik and Woolf's third criteria, we then considered whether beliefs which met the two previous criteria could be changed by giving evidence or information to strengthen or discount a belief.

Results

Descriptive Analyses

Prior knowledge of BM donation was very low ($M = 2.6$, $SD = 1.3$) with 79.1% of participants self-reporting a score of 3 or below on the 7-point scale. Participants had slightly weak intentions to join the ABMDR ($M = 3.32$, $SD = 1.38$). Most behavioural, normative, and control beliefs were correlated significantly with non-donors' intentions to join the registry.

Multiple Regression Analyses Predicting Non-Donors' Intentions to Join the ABMDR

Behavioural beliefs. The linear combination of behavioural beliefs explained 22% of non-donors' intentions to join the ABMDR (Table 2 displays F and beta statistics). Only one behavioural belief was significant and endorsed partially or fully by 63.1%; the more non-donors thought BM donation was an invasion of their body and a likely consequence of joining the registry, the less they intended to join (36.9% did not hold this belief strongly).

Normative Beliefs. Normative beliefs explained 27% of non-donors' intentions with partner and parents as the two significant normative influences. Less than a quarter of non-

donors fully or strongly endorsed partner (9.5%) or parents (14.1%) as informing their intentions.

Control Barrier Beliefs. Control barrier beliefs explained 27% of variance in non-donors' registering intentions. The less non-donors anticipated pain or side effects from giving blood, lacked knowledge about BM registration, or believed effort was required to register, the stronger their intentions to register. A small proportion fully or strongly endorsed these beliefs (Table 2).

Control Motivator Beliefs. Control motivator beliefs explained 29% of variance in non-donors' intentions to join the ABMDR. One belief, 'information about how to register', was a significant and positive predictor of intentions and was fully or strongly supported by 23.7% of non-donors.

Discussion

New members on the BM registry are needed to allow sufficient diversity to meet patient needs (ABMDR, 2010b). We examined non-blood donors' intentions to join the ABMDR and their associated behavioural, normative, and control beliefs. Using Hornik and Woolf's (1999) criteria, and consistent with prior BM donation research (e.g., Glasgow & Bello, 2007; Norvilitis & Riley, 2001), we identified key behavioural (bone marrow donation as an invasion of the body), normative (support from parents), control barrier (pain/side effects), and motivator (knowledge about how to register) target beliefs significantly associated with non-donors' registering intentions (criteria 1). These beliefs were not endorsed by a substantial proportion of non-donors (criteria 2), suggesting the potential to introduce information or evidence encouraging belief change (criteria 3). Based on our findings several strategies can be offered for intervention.

Strategies for intervention

Just over a third of non-donors *disagreed* with the behavioural belief that BM donation is an invasion of their body. Increasing non-donors' knowledge about less invasive methods of BM donation may be useful such as leukapheresis (blood is extracted through a vein in the arm to allow separation of stem cells from other blood components, for transplant) (ABMDR, 2010a) compared to the more well-known form of BM donation (requiring general anaesthetic for blood stem cell extraction from marrow in the pelvic bone cavity which occurs via needle and syringe) (ABMDR, 2010a).

Only a small proportion of non-donors believed their partner and parents would support their decision to join the registry. While it is unclear whether this perceived disapproval is due to concern for donor wellbeing or potential risks associated with BM donation, it suggests the need to increase perceived approval from important others (Glasgow & Bello, 2007) potentially by encouraging parental or partner involvement in the decision or asking a parent or partner along to the blood donation collection facility for moral/emotional support (Sojka & Sojka, 2008). Sharing the experiences of family members of BM donors who were concerned for their loved one's wellbeing but ultimately supported their decision may also help to increase perceptions of family approval for joining the registry (Hyde & White, 2009b).

Our findings suggest that information or interventions to overcome anticipated fears about blood donation may also be needed. Only a small proportion of non-donors did *not* believe anticipating pain or side effects from giving blood would stop them from joining the registry, suggesting that a much larger proportion of non-donors fear the process (Ditto, France, & Holly, 2010; Harrington et al., 2007; Masser et al., 2008); a finding that is consistent with prior research showing that non-donors who anticipate more anxiety about donating blood are less inclined to donate (Robinson, Masser, White, Hyde, & Terry, 2008). Offering non-donors strategies to overcome the anticipated negative experience of blood

donation may be worthwhile (Ditto et al., 2010; France, France, Kowalsky, & Cornett, 2010; France, Montalva, France, & Trost, 2008; Masser & France, 2010). For example, Masser and France (2010) found a modified blood donation coping brochure incorporating a narrative for first-time donors was more successful than the standard blood service and control (exercise) brochures in increasing efficacy for donation and reducing anticipated vasovagal reactions. There is potential for such coping brochures to be applied in the BM context and distributed at the time an appointment is made to give a blood donation or as a resource on the BM registry website.

Few non-donors believed the amount of effort required and lack of knowledge about how to register would *not* prevent them from registering. In other words, these barriers would stop many non-donors from joining the registry. These beliefs are amenable to change through the provision of new information or evidence; a quarter of non-donors would be motivated to register if information about how to join was provided. Testimonies from non-donors who have joined the registry could highlight registering as a straightforward process that can be time effective if planned in advance and to reduce fear or apprehension about the blood donation and registration process (Hyde & White, 2009b; Robinson et al., 2008).

Limitations and Future Directions

Despite its strengths, the results of the study should be interpreted with caution. Our focus on intentions to join the registry rather than registering behaviour was not ideal; however, intentions have a strong relationship with behaviour in donation contexts (e.g., Schlumpf et al., 2008). Furthermore, joining a BM registry is a behaviour that people will likely only perform once which reduces the chances that prior behaviour is inflating the relationship between beliefs and intentions (Weinstein, 2007). The sample comprised non-donors who were predominantly female and university students; future research should address these limitations.

Beliefs for non-donors and experienced donors may differ (Masser et al., 2008).

Experienced donors may find the required blood sample to be less challenging than first-time donors and future research should compare the beliefs of these two groups. Qualitative methods could be used to better understand normative support in this context since few non-donors perceived approval from important others for joining the BM registry. It is possible that the wishes of significant others may be unknown or may potentially be more supportive than might be perceived by non-donors. Another essential avenue for future research is to consider beliefs related to each step of the BM registration process. In the current study, we considered all three steps simultaneously (an approach used in other donation contexts; Hyde & White, 2007; 2009a) which precluded a separate examination of beliefs that could offer further insight into the motivations underlying registration decisions. Finally, overcoming barriers to joining the BM registry is a critical avenue for future research which could involve piloting a donation coping brochure as well as the standard BM registry brochure to alleviate anticipated fear about donating blood; an essential step in registering.

Overall, this study has identified a range of beliefs that could serve as useful targets to increase intentions to register as a BM donor among people who have never donated blood. Appropriate measures to overcome the barriers to joining the registry may increase non-donors' intentions to join and potentially increase the chances that a positive donor match will be found via donor registries for those individuals needing a BM transplant to save or improve their quality of life.

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Table 1

Means, Standard Deviations and Correlations for Non-Donors' (N = 150) Belief Items and Intention to Join the Australian Bone Marrow Donor Registry among Non-Donors

Belief-item	<i>M</i>	<i>SD</i>	Correlation (<i>r</i>) with Intention
Behavioural beliefs			
Saving or improving the lives of other people	5.79	1.22	.12
Being unable to change my decision once I have registered	3.58	1.67	-.12
Having to undergo surgical procedures if I am a donor match	4.79	1.65	-.01
Enabling efficient procedures to find a donor match	4.87	1.30	.06
Experiencing health risks or complications as a result of donating BM	3.81	1.62	-.20*
Knowing someone will donate to me if I need it	4.59	1.36	.07
Thinking BM donation is an invasion of my body	3.43	1.82	-.43***
Experiencing pain as a result of donating BM	5.08	1.84	-.21**
Experiencing pain or side effects as a result of giving blood	4.52	1.84	-.21**

Normative beliefs			
Family	3.65	1.64	.43***
Partner	3.62	1.50	.45***
Parents	3.64	1.67	.45***
People who need or have received a BM transplant	6.00	1.44	.20*
Friends	3.79	1.40	.40***
Doctors and other medical professionals	4.99	1.61	.26***
Church and religious group members	4.91	1.90	.16*
Australian BM Donor Registry	4.97	1.80	.03
Control barrier beliefs			
Anticipating pain as a result of donating BM	5.19	1.89	-.37***
Thinking I am ineligible to donate blood or BM	3.84	1.68	-.05
Lack of knowledge about the BM donation process in general	4.93	1.70	-.08
Anticipating pain or side effects as a result of giving blood	4.81	1.94	-.41***
Amount of effort required	4.78	1.49	-.27***
Lack of knowledge about how to register	4.65	1.63	.08

Fear of seeing blood	3.26	2.08	-.25**
Having too many constraints on my time	4.89	1.67	-.17*
Feeling fearful about needles or blood (e.g., phobia)	4.21	2.22	-.30***
Being unaware of where a blood collection centre is located	4.14	1.75	.01
<hr/> Control motivator beliefs			
Hearing about people who have benefitted from a transplant	5.48	1.22	.39***
Knowing someone who needs a transplant	6.31	1.04	.25**
Information about how to register	4.69	1.34	.49***
Knowing more information about the donation process and the risks involved	5.04	1.35	.39***
Having friends/family who would join the registry with me	5.02	1.50	.20*
Personally knowing the transplant recipient	5.92	1.52	.05

* $p < .05$. ** $p < .01$. *** $p < .001$.

Table 2

Summary of Key Beliefs Identified in Multiple Regression Analyses Informing Non-Donors' (N =150) Intentions to Join the Australian Bone Marrow Donor Registry

	β	R^2	Df	F	% full belief ^b	% strong belief ^c	Total % believe
Behavioural beliefs		.22	9,136	4.37***			
Saving or improving the lives of other people	.05				-	-	-
Being unable to change my decision once I have registered ^a	-.06				-	-	-
Having to undergo surgical procedures if I am a donor match ^a	.14				-	-	-
Enabling efficient procedures to find a donor match	.07				-	-	-
Experiencing health risks or complications as a result of donating BM ^a	-.11				-	-	-
Knowing someone will donate to me if I need it	.07				-	-	-
Thinking BM donation is an invasion of my body ^a	-.35***				18.8%	18.1%	36.9%
Experiencing pain as a result of donating BM ^a	-.12				-	-	-
Experiencing pain or side effects as a result of giving blood ^a	-.07				-	-	-
Normative beliefs		.27	8,137	6.23***			

Family	-.22	-	-	-
Partner	.27*	1.4%	8.1%	9.5%
Parents	.40*	2.0%	12.1%	14.1%
People who need or have received a BM transplant	.10	-	-	-
Friends	.06	-	-	-
Doctors and other medical professionals	.18	-	-	-
Church and religious group members	-.14	-	-	-
Australian BM Donor Registry	-.15	-	-	-
Control barrier beliefs		.27	10,13	4.91***
Anticipating pain as a result of donating BM ^a	-.05	-	-	-
Thinking I am ineligible to donate blood or BM ^a	-.05	-	-	-
Lack of knowledge about the BM donation process in general ^a	-.04	-	-	-
Anticipating pain or side effects as a result of giving blood ^a	-.27*	6.0%	11.4%	17.4%
Amount of effort required ^a	-.22*	3.4%	2.7%	6.1%
Lack of knowledge about how to register ^a	-.30**	4.7%	9.4%	14.1%
Fear of seeing blood ^a	-.09	-	-	-

Having too many constraints on my time ^a	-.11	-	-	-
Feeling fearful about needles or blood (e.g., phobia) ^a	-.03	-	-	-
Being unaware of where a blood collection centre is located ^a	.06	-	-	-
Control motivator beliefs	.29	6,139	9.59***	
Hearing about people who have benefitted from a transplant	.12	-	-	-
Knowing someone who needs a transplant	.14	-	-	-
Information about how to register	.38***	8.8%	14.9%	23.7%
Knowing more information about the donation process and the risks involved	.17	-	-	-
Having friends/family who would join the registry with me	-.17	-	-	-
Personally knowing the transplant recipient	-.14	-	-	-

Note. ^a Negatively worded item (i.e., reversed item). ^b Items measured on a 7-point Likert scale. A score of 7 represents full acceptance of a belief item, with the exception of reverse scored items where a score of 1 represents full acceptance of a belief. ^c Items measured on a 7-point Likert scale. A score of 6 represents strong acceptance of a belief item, with the exception of reverse scored items where a score of 2 represents strong acceptance of a belief.

* $p < .05$. ** $p < .01$. *** $p < .001$.