

# Patient Perspectives on the Usefulness of Routine Telephone Follow-Up as Psychosocial Support for Hematologic Malignancies: Australian Findings

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Since the 1990s, telephone interventions have been used as a potentially effective way to provide psychosocial care for patients with cancer (Gotay & Bottomley, 1998). That approach was thought to be particularly promising for patients who may not otherwise receive psychosocial care because of factors such as geographic isolation, physical limitations, or a lack of comfort with face-to-face approaches. However, situating routine telephone follow-up supportive care for patients with hematologic malignancies in the literature is complex because the extant research covers many topics with little commonality. The majority of research conducted on telephone follow-up care for patients with cancer focused on clinical care rather than supportive care management. In the clinical literature, most research, with the exception of Compaci, Ysebaert, Obéric, Derumeaux, and Laurent's (2011) study, rarely mentions research for telephone follow-up as supportive care for patients with hematologic malignancies.

Available research on telephone supportive care in place of clinical care for patients with cancer largely focused on diagnostic groups other than hematologic malignancies (e.g., colorectal cancer, prostate cancer, gynecologic cancers, breast cancer) (Crane-Okada et al., 2012; Cusack & Taylor, 2010; Pistrang, Jay, Gessler, & Barker, 2012; Scura, Budin, & Garfing, 2004). Each type of cancer has specific factors that affect the psychosocial challenges of the disease and its treatment that render the generic term "cancer" meaningless and make generalizations about supportive care strategies less useful.

Considerable variation exists in the literature for patients' preferences for supportive services. Telephone support can be offered to patients and caregivers individually or as a group (Gotay & Bottomley, 1998; Walsh & Schmidt, 2003). Extensive research documented the different psychosocial and supportive care needs for patients and caregivers, and participants differed in preferences for an individual or group approach.

**Purpose/Objectives:** To explore the use of routine telephone follow-up as a supportive care strategy for patients with hematologic malignancies from the patients' perspectives.

**Research Approach:** A qualitative design based on a series of open-ended interviews and one focus group.

**Setting:** Leukaemia Foundation of Queensland, Australia.

**Participants:** 50 participants recruited from the Leukaemia Foundation of Queensland database that represented a sample of major diagnostic groups, age, gender, and geographic location of patients with hematologic malignancies.

**Methodologic Approach:** Interviews and focus groups were open-ended and were recorded, transcribed verbatim, coded, and thematically analyzed to form the basis of the findings.

**Findings:** The majority of participants in the study saw a perceived benefit in regular telephone follow-up as a supportive care service. Benefits included the positive aspects of individualized attention, potential support created for those not open to conventional types of support, and the positive effects of allowing support organizations to keep track of patient progress. However, some participants did not want to receive regular telephone follow-up support because of a desire to move on and access to other support through friends, family, or healthcare professionals.

**Conclusions:** The results from the current study affirm previous research. Attitudes toward a telephone follow-up support service vary from patient to patient. Research demonstrates that patients with cancer responded with attitudes that range from favorable to unfavorable toward the benefits and usefulness of telephone support.

**Interpretation:** Oncology nurses provide supportive care for patients with hematologic malignancies, and they serve as a key professional group to provide follow-up telephone supportive care. Based on the findings from the current article, oncology nurses who provide supportive care should be aware of differing attitudes among patients with hematologic malignancies toward telephone follow-up support. Nurses participating in support initiatives should recognize the notion of patient receptivity and how it affects telephone support strategies.

**Key Words:** hematologic malignancy, telephone follow-up, supportive care, psychosocial, qualitative research

Many professional groups offer supportive care by telephone, including peers (Pistrang et al., 2012), oncology nurses (Radziewicz et al., 2009), medical surgical nurses (Walsh, Estrada, & Hogan, 2004), nurse specialists (Cusack & Taylor, 2010), psychologists (Arnaboldi et al., 2010), and cancer helpline counsellors (Jefford, Kirke, Grogan, Yeoman, & Boyes, 2005; Livingston et al., 2010). Those groups have different education and training backgrounds, levels of expertise, and roles and objectives informing their work in telephone support.

The timing and regularity of telephone calls should be considered. The available research explored a variety of time periods in which telephone follow-up is maintained, ranging from one-off post-treatment calls (Salonen et al., 2009), biweekly post-treatment calls (Compaci et al., 2011), at intervals throughout treatment (Livingston et al., 2010), and at one year postdiagnosis (Coleman et al., 2005; Scura et al., 2004). In some cases, the telephone support service was a helpline that individuals could call at any time (Hornsby & Fletcher, 2005).

No other available literature discussed supportive care delivery for patients with hematologic malignancies from the perspective in the current article. In addition, the available literature is based on the assumption that the individual agrees to or wants to receive telephone support. The current study explored the fundamental question that should be asked prior to the implementation of a telephone supportive care initiative, which is, "Is a telephone service actually wanted by patients?" The insights are a subset of findings taken from a study funded by the Leukaemia Foundation of Queensland (LFQ) that explored the survivorship experience for patients diagnosed with hematologic malignancies.

Additional findings from the study (McGrath, 2013; McGrath & Holewa, 2011, 2012) highlighted four factors that directly relate to the potential importance and effectiveness of routine follow-up telephone calls for patients with hematologic malignancies. Survivorship is not just a point in time; it starts at diagnosis and continues over the course of treatment and into survivorship. The needs of individuals diagnosed with a hematologic malignancy change over time depending on whether they are at the point of diagnosis, treatment, remission, relapse, or palliative care. A positive relationship with LFQ support workers can be a lifeline when a patient with a hematologic malignancy has a need for additional assistance. However, patients differ in their receptivity to any LFQ initiative. The term "receptivity" refers to the range of factors (e.g., individual, social, geographic) that affect an individual's desire or ability to receive or engage with supportive care services designed to meet his or her needs (McGrath, 2013). The expectation was that routine follow-up telephone calls could act as supportive care from the point of diagnosis, foster a strong relationship with the LFQ, provide feedback on changing needs, and

serve as an effective way to reach individuals with low receptivity toward other types of supportive care. To understand the viability of routine follow-up telephone calls, patients were given the opportunity to comment on the usefulness of the strategy from their perspective. The findings documented in the current article explore attitudes toward the possibility of telephone follow-up. This article makes a contribution to the literature by providing a clear focus on five dimensions of telephone follow-up for patients with cancer (i.e., diagnostic groups that include hematologic malignancies, psychosocial rather than clinical support, support provider as a trained supportive care counselor, routine telephone calls, and routine telephone calls that occur once a year).

## Research on Follow-Up Telephone Calls

The aim of the parent study was to document and explore issues associated with the survivorship experience for patients with hematologic malignancies. The research explored the patient perspective on the value of a routine, annual follow-up telephone call from LFQ support staff. A qualitative methodology was used that included a series of open-ended interviews and one focus group. Interviews were recorded and transcribed verbatim, then coded and thematically analyzed. A full discussion of the research methods is provided in previous articles on the study (McGrath, 2012; McGrath, Hartigan, Holewa, & Skaparis, 2011, 2012).

Participants were sampled from a patient database maintained by LFQ. The participants were enrolled by two project officers who were under contract with Central Queensland University and independent of LFQ. Potential participants received a letter from LFQ that informed them of the study and stated that they could opt out. Any individual who did not want to be involved was deleted from the list. After excluding the details of individuals who chose to withdraw from the study, the database of patient contacts was given to the project officers for participant selection. The actual identity of the participants remained confidential because the researchers did not provide LFQ with any details of the participant selection. Potential participants were given a written project description and consent form and received an initial telephone call inviting participation in the research. Prior to interviewing, participants were informed of their ethical rights (e.g., informed consent, confidentiality, right to withdraw), and individual consent was obtained. The study was approved by Central Queensland University Human Research Ethics Committee.

All participants met survivorship criteria in that they were adults with hematologic malignancies and were at least one year postdiagnosis. Researchers contacted 118 potential participants, with 14 declining participa-

### Support for the Idea

"That would have been very good. Yes, that would work."

"I'd definitely think about it, put it that way."

"I can see value in [that]."

"It would appeal to me. I think it's a good idea."

### Provides Personal Attention

"That'd be fine. . . . Everybody's got to cope with an ego and their little few minutes of fame, and, you know, if people are interested in you, that's all part of that."

"I do. I think that's a good idea. . . . I can't say [it] makes people feel important, but [it] makes people feel as though someone else is thinking about them."

### Helpful for People With Little Support

"I think, you know, for people who don't have a lot of support, if someone is actually constantly ringing them, that's probably a really good thing. . . . I mean, a lot of people probably don't know where to go for things, so if someone can offer it to them and say, 'This is how you go about it,' . . . Makes things a lot easier."

### Provides One-on-One Contact

"I think, because it's more one-on-one and you're not quite, you don't have all eyes looking on you . . . it's not quite as intimidating."

"A telephone link-up probably would suit, yes, and that's a really one-to-one, personal sort of thing, rather than a group atmosphere."

### Particularly Useful After Treatment

"My husband says, 'Is that all you're going to eat tonight?' And I go, 'Well I can't eat anything more.' . . . And I think, you know, they're a bit unsure at the time, so that might be a time when a follow-up phone call [is good]."

"I think that's probably a good thing. I mean, a year after treatment, you're still very fresh, and people are still really going through it, so it is very relevant at that point."

"I think the Leukaemia Foundation [of Queensland] can do as much as they can during treatment. I think just a few follow-ups after your treatment, just to see that your family's okay, you're okay, you're back in the workforce, you're back in the community doing what you do best."

### The Need for Involvement Is Ongoing

"I don't think you can forget about it completely and move on, and I don't think you should. And I don't know if getting involved in things, even if you are trying to move on, I don't think it's a bad thing."

### Maintains a Link With the Leukaemia Foundation of Queensland

"I stayed in contact with the Foundation for quite a long time after the transplant[ation]."

"Particularly helpful if others with the same diagnosis do not live locally."

### Provides Information

"Look, I think it's good because I'm a big believer in, I mean, the more information a person has . . . it could be anything, anything that either could make your life easier or make you aware. . . . I think [routine calls are] a good thing."

### Can Help Support Workers Know How People Are Doing

"Because it's probably just as helpful for [the Leukaemia Foundation of Queensland] as it is for the person that's been through it because they can say, 'Oh, well, this person's going along fine, and he hasn't had any problems for 12 months. This person is not going as well.' . . . That would help with research, I would imagine."

## Figure 1. Positive Reactions to Telephone Follow-Up

tion and 54 unable to be contacted because of a change in contact details. Fifty participants (26 male, 24 female) represented major hematologic diagnostic groups, including multiple myeloma (n = 15), lymphoma (n = 14), and leukemia (n = 17). Types of lymphoma included Hodgkin and non-Hodgkin, and types of leukemia included acute lymphoblastic, acute myeloid, chronic lymphoblastic, and chronic myeloid. Four patients were diagnosed with other hematologic malignancies, including myelodysplastic syndromes. Eleven participants had undergone a bone marrow transplantation, and 15 had undergone a stem cell transplantation (allogeneic or autologous). All participants were from Queensland, Australia. Because of the unique geography, population, and service provision patterns of Queensland, a customized regional classification system was designed to ensure that the sample included participants with varying levels of access to hematologic services based on their home address, as well as a representation of varying ages across the adult lifespan.

## Results

### The Perception of Benefit

The majority of participants perceived benefit from routine follow-up telephone calls. The reasons for the perceived benefit included that most people would enjoy the individual attention of a telephone call, that it would be an effective medium for individuals with little support or who prefer one-to-one contact, that an ongoing need for support exists, that it allows individuals to stay in contact with LFQ, that it can provide participants with personalized information, and that it can help LFQ support workers know how patients are progressing (see Figure 1). Participants noted that the critical time for starting the telephone calls was after treatment, particularly when the patient arrives home from the hospital.

### Rejection of Routine Follow-Up Calls

Many individuals indicated that they would not want to receive follow-up telephone calls. The reasons why individuals did not support the idea included a desire not to focus on the disease and treatment in favor of moving on, as well as the thought that they would talk to friends, family, or doctors if problems arose (see Figure 2). In addition, those participants would not want regular calls from LFQ or follow-up calls from support workers, and they believed that other patients would need those supportive services more.

## Discussion

Because the research literature on telephone support includes diverse diagnostic groups, aims of the support service, providers of the support, and recipients of the

support, making definitive statements about the positive benefits of such an intervention is difficult. The current article discusses existing literature that examines telephone follow-up for patients with cancer provided by a professional caregiver. Within that literature, evidence exists that suggests telephone support benefits patients, which affirms the perspectives of participants in the current study who support routine telephone follow-up.

Research by Chamberlain Wilmoth, Tulman, Coleman, Stewart, and Samarel (2006) indicated that in patients with breast cancer, telephone support improves attitudes toward the disease and toward their relationships with significant others. Similarly, Salonen et al. (2009) demonstrated that telephone support reduced anxiety for patients with breast cancer and improved body image. Several other studies indicated that telephone support can be an effective medium for providing support, particularly for those with limited access to supportive services because of geography, work demands, or family situations (Arnaboldi et al., 2010; Cusack & Taylor, 2010; Scura et al., 2004; Chamberlain Wilmoth et al., 2006).

As Pistrang et al. (2012) determined, the success of telephone follow-up is dependent on the effectiveness of the working relationship between the support provider and recipient. For an organization such as LFQ to provide telephone follow-up support throughout the cancer continuum, a positive relationship must exist between the support provider and patient. Additional findings from the parent study discussed in the current article indicated that the participants perceived the support workers at LFQ as skilled at reaching out to help patients diagnosed with hematologic malignancies and their families. Participants noted that LFQ support workers had "skilled knowledge of what people are going through," and were aware of the resources that can be used and able to accurately assess whether an individual was in need of help (McGrath & Holewa, 2011, p. 130).

However, some participants said that they would not want telephone follow-up or felt that other patients could benefit from the service more. The notion of a lack of benefit from telephone follow-up, particularly for those who are resistant to the idea, also is noted in the literature. Some studies indicated that telephone follow-up does not provide any psychological assistance (Coleman et al., 2005; Livingston et al., 2010). Research indicates that patients may prefer face-to-face assistance rather than telephone support, and that the benefits of telephone follow-up have not been proven (Arnaboldi et al., 2010; Shepherd, Goldstein, Olver, & Parle, 2008). Additional research is required to determine whether the intervention is more effective for patients who do not have psychosocial support or have unmet information needs (Livingston et al., 2010). The literature calls for additional research to assess the

impact of telephone support for patients with cancer (Finfgeld-Connett, 2005; Livingston et al., 2010).

## Implications for Nursing

Healthcare providers who wish to provide telephone follow-up should be respectful of patients who do not want routine telephone calls. Supportive care initiatives should involve strategies (e.g., opt-out options) to ensure the privacy of those individuals who do not want telephone follow-up. The use of telephone follow-up for patients with cancer as a supportive care strategy and its psychosocial health implications is an area that requires additional research. The purpose of the current article is to make a contribution to the body of work on telephone follow-up support for patients with cancer, particularly those with hematologic malignancies. This article focused on patient attitudes toward telephone follow-up.

### Lack of Support for Idea

"In my case, no, I don't believe [it would help]."

### Does Not Like Focusing on the Disease and Treatment

"I don't really like to bring it up too much, so not really."

### Has Others to Provide Information, Medical Advice, and Support

"No, I don't know what they could do. I'd be giving them information, what would they be giving me? Hopefully [if I had a problem], we'd know enough people now that if [my doctor] can't do it, and a call to the hospital can't do it, you know you'd work your way through until you find somebody who could solve whatever was troubling, worrying you."

"If they could answer specific questions, but I find most of these say, 'Aw, ask your doctor,' so what's that point? I wouldn't mind, but I don't think when you're seeing the doctor regularly, if you've got an issue, you'd probably go to your doctor or ring down to your specialist, I would think. I can't see much [benefit] from my point of view."

### Wouldn't Want Regular Calls

"I don't mind anybody calling me, but not as a regular, 'Oh, I must call him.' I wouldn't like that. If they say, 'Oh, look, I've your name here, how you're getting on.'"

### Interferes With the Process of Getting on With Life

"It probably would feel good, but then, like I said, it'd probably be like a nuisance call. Like, you're over your cancer. . . . You just want to get on with your life. You don't want someone bothering you from, you know, the past."

### Not Necessary

"No, I don't need that at all. . . . Me, personally, no."

"[At] this stage, I don't think I need any."

### Uses Up Resources for Others Who Need Telephone Contact

"I don't think so. I think we're quite alright as we are. If they do, I wouldn't knock it back. You know, I wouldn't say, 'No, I don't want to hear from you,' or anything like that, but they've probably got more, other people that are more . . . needing of that sort of thing . . . rather than do it for me. Like, they might have people who are worse off than me . . . who might need that more often."

## Figure 2. Negative Reactions to Telephone Follow-Up

## Knowledge Translation

Receptivity plays a vital role in patient attitudes toward telephone follow-up support.

The findings highlight the complexity of individual responses to routine follow-up telephone calls by documenting the perception of benefit and the rejection of the idea.

The current article provides information on the specific diagnostic group of hematologic malignancies.

## Conclusions

Routine telephone follow-up as a supportive care service has the potential to reach a wide range of individuals in a user-friendly manner. However, healthcare providers should take into account the differing attitudes toward telephone follow-up. As demonstrated by the findings in the current article, participants expressed divided opin-

ions on the benefits of telephone follow-up. Although some individuals were in favor of the intervention and highlighted the usefulness of telephone support, others did not find it to be desirable or necessary.

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