Creating a language for ‘spiritual pain’ through research: a beginning

Abstract The findings presented in this discussion seek to make a contribution to fostering an appreciation of the importance of research on spirituality, a previously neglected dimension of health care. Qualitative research methodology based on open-ended interviews with 12 survivors of haematological malignancies was used. The interviews were transcribed verbatim and thematically analysed using the NUD*IST computer package. The preliminary findings from the study indicate a need for the development of a new language for articulating spirituality. The present discussion is an introductory attempt to begin to explore the notion of, and language for, the idea of ‘spiritual pain’. The findings indicate that individuals need a strong sense of meaning-making and connection with life to be able to deal with the demands of aggressive, invasive treatments. Such a connection can be threatened by a break with the normal or expected relationships and satisfaction with life through physical, identity, relational and existential challenges and losses. When the disconnection is acutely painful (a subjective phenomenon depending on the individual) it then is experienced as spiritual pain, creating a void that challenges the individual’s ability to derive any meaning from their existence. This study is seen as preliminary work, the first step in a series of articles aimed at beginning to develop, through research, a language of spiritual care.

Keywords Spirituality · Spiritual pain · Haematology · Psychosocial · Survivors

Introduction

The lack of attention to research on spirituality is an issue that has been articulated in the health care literature for many decades [2, 6, 14, 17, 27, 29, 30, 31]. Dubbed the ‘ignored dimension’ by Soeken and Carson [29], only in recent years has the notion of spirituality been explored by means of academic research [8, 17, 18, 21]. The findings presented in this discussion, which are taken from a recent and ongoing programme of research on spirituality, seek to make a contribution to fostering an appreciation of the importance of research on this previously neglected dimension of health care. As the above introductory quote suggests, the preliminary findings from the programme indicate that there is a need for development of a new language for articulating spirituality. The present discussion is an introductory attempt to begin to explore the notion of, and language for, the idea of spiritual pain.

The work that does exist has led to some progress in defining and understanding the notion of spirituality. This discussion will be informed by recent definitions that posit ‘meaning-making’ and ‘experience as a person’ as the starting point for the exploratory research on

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There probably are the words but I don’t know, sometimes I... ahhh... struggle a bit with saying how I feel.
(Research participant)
spirituality [1, 4, 12, 16, 24, 26, 33, 34, 35]. Concisely stated, ‘spirituality is defined as that part of the self where the search for meaning takes place’ [34]: it is ‘the organising centre of people’s lives’ [12]. Preliminary definitions from the literature indicate that spirituality is broader than religion and relates to the universal quest to make sense out of existence [11, 25], a characteristic of human ‘being’ [7, 28]. Indeed, early findings from the research study reported in this paper indicate that for most participants spirituality is ‘quintessentially of the ordinary’ and has to do with the meaning individuals are making of their connection with the ‘here and now’ [22].

The Research

This research project represents the first time substantial funds have been provided by a major Australian cancer research organisation for work on spirituality. The study, funded by the Queensland Cancer Fund for 2 years and conducted at the University of Queensland, examines the relevance of the notion of spirituality and spiritual pain for hospice patients (arm A) and their carers (arm B), the health professionals who look after them (arm C), cancer survivors (arm D), and patients undergoing curative care in a hospital setting (arm E). The findings reported in this paper are presented from the arm of the research that explores aspects of spirituality in relation to survivors (arm D).

The participants in this arm of the study were enrolled through the support worker at the Leukaemia Foundation of Queensland (LFQ). The support worker is closely involved with individuals who have survived a haematological malignancy through her work with the survivors’ support group (TISH – Thankfully I’m Still Here), the patient educational program (Taking Control), and individual counselling. There was no screening of participants. The participants selected were the first 12 on the LFQ’s alphabetic list of ‘survivors’, which is kept up to date by the support worker. Prospective participants were contacted and told of the study and invited to participate in an interview. All of the participants contacted agreed to participate (N=12), giving a participation rate of 100%. Participants were informed of their ethical rights (such as informed consent, confidentiality, right to withdraw) before agreeing to participate, and written consent was obtained from each prior to the interview. The university ethics committee has approved the study, and the ethics committee has ratified project descriptions and consent forms.

Target population

All of the participants had been diagnosed with a haematological malignancy; such malignancies are cancers of the blood and blood-forming tissues and include the leukaemias, lymphomas and myelomas [20]. Patients in these diagnostic groups face a potentially life-threatening condition and undergo risky, aggressive, invasive treatment protocols, including bone marrow transplantation, total-body irradiation and high-dose chemotherapy, that extend over lengthy periods of time [19]. Consequently, this group of survivors would have experienced a potential confrontation with death both at the point of diagnosis of their life-threatening condition and during their risky high-tech treatments. For the purpose of this article, the term ‘survivor’ means a person who is no longer undergoing curative care and is at least 3 years post-treatment. As the demographics show, the majority of the participants qualify for the clinical notion of ‘cure’; that is to say that they have achieved a 5-year disease-free interval.

Most of the participants were male (n=8), with less than half female (n=4), and represented a range of haematological malignancies including chronic myeloid leukaemia (n=5), acute lymphoblastic leukaemia (n=2), acute myeloid leukaemia (n=2), multiple myeloma (n=1), non-Hodgkin’s lymphoma (n=1) and Ewing’s sarcoma (n=1). The ages of the participants ranged from 25 to 60 (25–29, n=3; 35–39, n=2; 40, n=3; 50–55, n=3; 60, n=1). Most of the participants had been diagnosed from 3 to 8 years before the study (3 years, n=1; 4 years, n=1; 5 years, n=3; 7 years, n=3; 8 years, n=2), although for 2 the time since diagnosis was much longer (12 years, n=1; 15 years, n=1). The majority have undergone at least one bone marrow transplantation (n=8), and all have experienced extensive chemotherapy and radiotherapy. More than half of the participants were 5 years or more post-treatment (5 years, n=3; 6 years, n=2; 9 years, n=1; 10 years, n=1), an important point in time that signals cure in oncology terms. However, 5 of the participants had not yet reached the 5 years post-treatment point (1 year, n=1; 3 years, n=2; 4 years, n=2).

Methodology

The meaning survivors are deriving from their illness experience has been documented through qualitative research using an open-ended interview with each participant. The interviews were conducted by a psychosocial researcher with a counselling background, a track record in spirituality research, and many years’ experience working with families coping with a member with a haematological malignancy. The time and location of the interviews were of the participants’ choosing. Each participant was encouraged to tell their story from the point of pre-diagnostic symptomatology up to the present with the opening prompt question: ‘Could you tell me of your experience, in your own words and in your own way, from the time you became aware that you were ill and how that has changed how you see the world and what you believe is important?’

The interviews were audio-recorded and transcribed verbatim. The language texts were then entered into the NUD*IST computer program and analysed thematically. A phenomenological approach was taken to the recording and analysis of the data. All of the participants’ comments were coded into free nodes, which were then organised under thematic headings. The coding was established by an experienced qualitative researcher. A second investigator for the project reviewed and validated the coding. There was complete agreement on the coding and on the themes that emerged. There were 75 free nodes created for the full analysis of the survivors’ transcripts; those of them that directly related to the topic ‘spiritual pain’ are presented here.

As inductive, phenomenological, qualitative work, the reporting of findings is based on a commitment to the participants’ point of view, with the researcher playing the role of co-participant in the discovery and understanding of what the realities of the phenomena studied are [5, 10, 13, 32]. Thus, a narrative account dominates, with a clear separation between the presentation of the exact words of the participants in the ‘Findings’ section and the interpretation in the ‘Discussion’ section [9]. For economy of presentation the selected nodes have been organised under categories that, when juxtaposed, build up an outline of the issues [3, 15].

Findings

Paradigm example of spiritual pain

The following are a series of statements by one participant, providing a paradigm example of the notion of spiritual pain developed from these data. The core